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University of Bath
Doctorate in Clinical Psychology

Critical Review of the Literature:

Psychological influences that may impact on sexual satisfaction and dysfunction in individuals identifying as transgender; A structured narrative review

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This journal specialises in a range of issues affecting individuals identifying as transgender therefore is an appropriate Journal to target

Abstract

Current theories, models and definitions of sexual dysfunction have been developed primarily based on heteronormative assumptions. This can be problematic when considering people who do not fall under such assumptions including those who identify as transgender; meaning people whose gender identity differs from their assigned biological sex. The current literature on transgender individuals largely focuses on the physical aspects of sexual functioning after sex reassignment surgery whilst negating the psychological factors that may impact on sexual functioning. The aim of this review was to fill this gap and consider what psychological factors may impact on sexual dysfunction and sexual satisfaction in the transgender population and how this fits with current theories and definitions of sexual dysfunction. Due to the limited research investigating psychological factors that impact on sexual functioning in transgender individuals, literature examining psychological issues impacting on sexual experiences in transgender people was reviewed and synthesized in order to consider how these applied to sexual dysfunction. The themes derived included challenging cissexual assumptions, the negative impact of cis-genderism, heteronormative impact on sexual experiences, the relational impact and body image. These findings suggest the importance of clinicians considering the cultural and contextual influences on sexual functioning. Further, this review highlights the limits of the current conceptualizations of sexual dysfunction and the importance of a holistic approach.

Introduction

Sexual dysfunction is highly common with prevalence rates up to 46% of the general population (Simons & Carey, 2001). Sexual dysfunction is associated with psychological distress due to its impact on sexual and relationship satisfaction and has been found to reduce quality of life (Althof et al., 2005; Laumann, Paik & Rosen, 1999). The diagnostic category of sexual dysfunction according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) consists of eight disorders summarised in three subgroups: sexual desire and arousal disorders (Hypoactive Sexual Desire Disorder; HSDD, Male Erectile Disorder, Female Sexual Arousal Disorder); orgasm disorders (Female Orgasmic Disorder, Male Orgasmic Disorder, Premature Ejaculation); and Genito-Pelvic Pain/Penetration disorders (Dyspareunia, Vaginismus). These symptoms must be present for at least six months (American Psychiatric Association, 2013).

Theories and Models of Sexual Dysfunction

Masters and Johnson (1970) were pioneers in researching the treatment of sexual dysfunction which led to their model depicting four stages of physiological arousal; excitement, plateau, orgasm and resolution. Their work has been highly influential with these four stages defining the disorders of sexual dysfunction, however, their participant sample consisted of heterosexual people who were willing to be observed undertaking sexual intercourse in a laboratory setting and consisted of women and men who were orgasmic during intercourse. This limited sample makes much of their research and treatment difficult to generalize to the wider population.

Further, there is a focus on genital responses whilst ignoring other key aspects of women's sexuality such as trust, intimacy and affection (Basson, 2000). These aspects have been researched as important aspects desired by women, however, these may be just as relevant in men. Studies have demonstrated that due to lower levels of testosterone women have a lower biological urge to desire sex in order to release sexual tension (Bancroft, 1980). However, desire for sexual experience can be due to numerous motivations that may be beyond sexual reason.

An influential model on sexual dysfunction has been presented by Barlow (1986) who emphasises the role of cognitive processes and anxiety. Research studies (e.g. Beck, Barlow & Sakheim, 1983; Abrahamson, Barlow, Beck, Sakheim & Kelly, 1985) have implicated certain factors that present differently between those who are

sexually functional compared to individuals who are experiencing sexual dysfunction. These include differences in affect during sexual stimulation, differences in reported sexual arousal, differences in perceptions of control over their arousal, differences in distractibility during sexual stimulation and differential sexual responding while anxious (Beck & Barlow, 1984). These findings suggest a working model of sexual dysfunction that is based on cognitive interference and anxiety. This is where demands for performance lead to an expectation of performance which results in negative affect, inaccurate and under reporting of arousal and perceived lack of control. This leads to an inattentional focus on the consequences of not performing or other non-erotic issues which increases autonomic arousal. This arousal leads to a further attentional focus on the consequences of not performing resulting in dysfunction (Barlow, et al.,1984).

The majority of evidence to support Barlow's model was collected from male participants and consideration of wider aspects and issues that may be relevant to sexual dysfunction have been ignored. For example, sexual dysfunction is influenced by a range of predisposing, precipitating, maintaining and contextual factors (McCabe, 2010). Predisposing factors may include prior life experiences such as abuse or attachment difficulties and precipitating factors may refer to an individual's vulnerability to certain circumstances. Maintaining issues can include performance anxiety, impaired self-image and fear of intimacy. Contextual issues include the current demands and stresses that impact on the individual including environmental issues and socio-cultural influences such as a conflict with values and societal taboos.

To incorporate the various psychological factors impacting on sexual dysfunction, McCabe (2007) developed a holistic model comprising of intergenerational, individual, and relational factors. Intergenerational factors include belief systems in the family and values associated with gender, intimacy and sexuality. The role of gender in the family during childhood can have a significant influence on what is regarded as appropriate sexual behavior in adulthood (Nelson, 1987). Individual factors include personal values on sexuality, perceptions on the sexual attractiveness and confidence in body image, sexual fantasies and overall physical health (McCabe, 2007). Relationship factors comprise of power dynamics, intimacy issues and anger. Negative reactions due to issues in these various factors can lead to strong emotions which can impede sexual functioning. The meaning constructed from these factors are important to assess when considering the impact on sexual functioning.

Critique of the sexual dysfunction literature

A major criticism of the current theories and models of sexual dysfunction and the research supporting them is that they almost exclusively focus on heterosexual individuals and are entirely focused on cis-gender individuals. Cis-gender refers to when people's biological sex is associated with their gender identity (Schillt & Westbrook, 2009). Further, much of the early research could be argued to be based on sexist, heteronormative assumptions about sexuality and what is viewed as sexual dysfunction (Boyle, 1993). In heterosexual sex, it has been historically perceived as male dominance and female submission (Boyle, 1993). Though there have been many positive changes, there are many assumptions and values that are still highly dominant today that impact on theory and treatment of sexual dysfunction. For example, the centrality around both partners experiencing an orgasm through heterosexual intercourse being the ultimate, natural goal in sex (Boyle, 1993). This assumption has led to the idea of females being described as more complex and problematic due to often "*needing"* clitoral stimulation to orgasm, often viewed as being slower to become aroused and more psychologically sensitive to sexual encounters (Kaplan. 1974).

Further problems are encountered when considering how this research area fits with non-heterosexual individuals. A survey of three hundred gay men was conducted where 35% reported a current sexual problem with 70% having a current or previous problem (Cove & Boyle, 2002). Out of all the problems described only 16% could be classified into a DSM sexual dysfunction disorder suggesting a limitation on the current conceptualization of sexual dysfunction. Further, a study demonstrated that sexual practices with gay men can be wide-ranging with intercourse being rated of a lower preference with no assumption that it will take place during sex (Davies, et al., 1992). There are difficulties applying sexual dysfunction research to non-heterosexual individuals and the need for more research and awareness into these issues. The concept of how this definition of sexual dysfunction fits with individuals who identify as transgender also warrants further investigation.

Transgender

Gender refers to the social and culturally constructed differences between males and females encompassing norms, roles and relationships (American Psychological Association, 2011) People's gender identity refers to people's sense of their own gender and how they choose to express it. For others, their gender identity may differ from their

assigned biological sex which is described as transgender. People who identify as transgender may express this in numerous ways which may include including social transitioning, psychologically transitioning, legal confirmation, seeking gender-confirming hormone therapy and/or gender confirming surgery. For the purpose of this review, transgender refers to those who wish to transition to the opposite sex from which they were assigned at birth.

Transgender and sexual health

Transgender people experience negative attitudes, prejudice and discrimination in healthcare. For example, a third of individuals in a survey of 27,000 transgender people in America disclosed a negative experience with a health care provider (James, et al., 2016). This results in people avoiding healthcare providers due to fear of a negative experience which is likely to be intensified when seeking sexual health services. Transgender people often fear negative judgments about their sexual decisions due to not fitting with conventional gender norms (Bradford, Reisner, Honnold, & Xavier (2013). There is a lack of training currently in psychology over working clinically with transgender individuals and awareness of their sexual health needs (Carroll & Gilroy, 2002). Further, there is a lack of sexuality training both in general healthcare professionals and in the field of psychology (Shaw, Butler & Marriott, 2008). There is a pertinent need therefore to increase knowledge and gain awareness about the psychological issues that may impact on sexual functioning and sexual satisfaction.

Previous Reviews

The vast majority of research literature on transgender sexual satisfaction and sexual dysfunction has focused on the physical and biological facets of sexual functioning after surgery. For example, a review by Klein and Gorzalka (2009) examined primarily the physical aspects of sexual functioning following gender-confirming treatment (GCT). They found that after GCT individuals had adequate levels of sexual functioning and higher rates of sexual satisfaction with comparable rates of HSDD to females in the general population. Other studies have found higher rates of HSDD in transgender individuals after GCT compared with the general population (e.g. Elaut, et al., 2008). De Cuyepere (2005) found overall an increase in sexual satisfaction though this did not necessarily always equate to an increase in sexual functioning. When considering difficulties in sexual functioning and satisfaction in the transgender

population little attention has been given to psychological influences. Further, the focus has been on those who complete GCT when many people who identify as transgender often do not complete GCT (Grant, Mottet & Tanis, 2011).

A scoping review on sexual health in transgender men at varying levels of GCT was conducted by Stephenson et al (2017) which focused on sexual behaviours, sexual identity, sexual function and transactional sex. The sexual function component of the study consisted primarily of studies examining the physical aspects of sexual functioning with limited consideration of wider psychological issues.

A related review was published by Thurston and Allen in December 2018. Their review systematically reviewed seven qualitative papers on the sexual experiences of transgender people during the gender transition process. Their two main themes were '*re-negotiating previous norms'* and '*establishing an identity*.' Thurston's et al., (2018) review provides information on the processes occurring with changes in sexuality during gender transition, however, it did not set out to consider specific psychological issues that may impact on sexual satisfaction and dysfunction. Further, Thurston's (2018) literature search was conducted in May 2015 and due to this being a rapidly expanding field with recognition for the need for studies that go beyond the biological facets, there have been subsequent publications. Despite some overlap of reviewing similar articles to the literature cited above, the current review will examine both quantitative and qualitative literature around psychological issues related to sexual functioning and appraise the findings with how they relate to current models and theoretical stances on sexual dysfunction.

Rationale and Aims of the current review

It can be hypothesized that people who identify as transgender may have experienced dysphoria and anxiety due to the mismatch between their biological sex and gender identity and this might include a range of issues impacting on their sexual health needs which warrant further investigation. This current review aims to collate research on transgender sexual experiences beyond focusing purely on the measurement of physical aspects of sexual functioning. Due to the limited research investigating psychological factors that impact on sexual functioning in transgender individuals, literature examining psychological issues impacting on sexual experiences in transgender people will be reviewed and synthesized in order to consider how these apply to sexual dysfunction and sexual satisfaction.

This review will also include studies which include the perspective of the partner of the transgender individual. This will enhance understanding of the relationship issues that impact on sexual satisfaction and dysfunction. McCabe's, et al., (2007) review reports that in the heterosexual population, there is evidence to suggest that relationship issues can cause sexual dysfunction. Further, they found that love and emotional intimacy have a key role in sexual satisfaction. Having a partner who identifies as transgender would bring up unique relationship issues that would impact on sexual satisfaction therefore including partners perspectives in this review would facilitate understanding in this area. Additionally, McCabe's (2007) model emphasis the importance of examining relationship factors such as power dynamics, intimacy and anger which could all impact on sexual dysfunction and satisfaction.

These studies will then be appraised in the context of how they fit with current theories and current definitions of sexual dysfunction. This review, therefore, aims to provide a detailed insight into the potential psychological factors of sexual functioning and satisfaction in this population, and that this will provide clinicians with greater awareness and knowledge into the specific pertinent issues to address when providing support for transgender people with sexual health concerns.

Method

The aim of this review was to synthesise psychological issues that may impact on sexual satisfaction and dysfunction in individuals who identify as transgender and appraise these issues in the context of current psychological theories of sexual dysfunction. The research questions therefore are:

1) What are the psychological issues related to sexual satisfaction and dysfunction for transgendered people?

2) How does this relate to the psychological theories of sexual dysfunction for cis-gendered individuals?

As there is little known about the psychological issues that impact on sexual satisfaction and dysfunction in transgender individuals, a broad search strategy was applied in order to decrease the risk of missing articles relevant to the research question. The databases used in the search was PsychINFO, pubmed and embase.

The search terms used included: transgender OR transsexualism OR transmen OR transwomen OR transmale OR transfemale OR ‘female to male’ OR ‘male to female" OR transvestism OR "transsex" OR transmasculine OR transfeminine AND sexuality OR sexual arousal OR sexual intercourse OR sexual dysfunction OR sexual functioning OR sexual pleasure OR sexual wellness OR sexual satisfaction OR sexual behaviours.

The search resulted in 8,212 papers from PsychInfo, 4,949 papers from Embase and 2,374 from Pubmed. This electronic literature search was carried out between August – October 2018. Duplicates and irrelevant articles to answering the research question were removed which resulted in 60 articles being considered. The 60 full text articles were screened which resulted in 42 being excluded resulting in 18 studies. The researcher also received an additional relevant journal through another source resulting in a final sample of 19 studies. Grey literature was included when searching which resulted in two unpublished dissertations being included in the final sample. The final sample consisted of 12 qualitative studies and 7 quantitative studies (see Appendix 1.1 for summary table of the included papers)

The eligibility form that was applied to these papers was:

Table 1:

Eligibility Form to determine inclusion or exclusion of studies

Question	**If yes**	**If no**
Is the study about sexuality or sexual experiences in a transgender population?		
Does the study include psychological reasons that could impact on sexual experiences, sexual functioning or sexual satisfaction?	Continue	Exclude
Has the study recruited participants who are transgender or/and their partners?	Continue	Exclude

Although a systematic search was undertaken, the papers identified were reviewed narratively. A narrative methodology was deemed appropriate given the broad research questions and the broad inclusion criteria which increases the potential for

subjectivity, though this was minimised through a sub-set of the journals being discussed for suitability for inclusion with the project supervisor. Further, given the current lack of research in this area papers were sought that included psychological issues impacting on sexual experiences and these have then been applied to appraise how they fit answering the research question. Given the small samples and disparate methodologies a narrative synthesis of the results was chosen. The key findings and themes relevant to the research question were identified. The themes were then discussed with the project supervisor who provided guidance with further synthesis and considerations.

Quality Assessment

The Critical Appraisal Skills Programme (CASP) was used to review the papers. The qualitative CASP was applied to the 12 qualitative papers and the cohort CASP was applied to the 7 quantitative papers. Please see Appendix 1.2 and 1.3. A cross was applied if the paper did not contain information to answer the question, it was rated '*unclear'* if there was a moderate amount of information but not answering all the issues sufficiently and finally a tick if the question was fully addressed. For the quantitative papers, certain CASP questions were not always applicable to the research study and therefore these were rated "*N/A*" in the table.

Quality Assessment of the Qualitative Studies

For the 12 qualitative studies, strengths included that they all had clear research aims, appropriate method, research design and recruitment strategy. However, some failed to include any information of the relationship of the researcher and how this impacted on the findings of the research (Bockting; 2009; Brown, 2010; Schillt & Windsor, 2014; Williams, 2013) whilst for others this did not contain enough information or was unclear (Doorduin & Van Berlo, 2014; Joslin-Roher & Wheeler, 2008; Riggs et al. 2015). The majority of the studies failed to provide an adequate account of the ethical issues with the exception of Bockting, (2009), Mendelson (2015), Riggs, (2015) and Rosenburg, (2019). The majority of the studies the analysis was clear with the exception of Bockting (2009), Pheiffer (2008) and Williams (2013). The majority of the studies gave clear findings with the exception of Pfeiffer (2008) and Rosenburg (2019). The value and implications of the research was explicitly discussed

in the majority or the studies with the exception of Doorduin & Van Berlo (2014), Rosenburg (2019) and Schilt & Windsor (2014).

Quality Assessment of the Quantitative studies

The quantitative studies that examined relationships between variables utilised a cross-sectional design meaning that conclusions cannot be drawn around the causality of the findings. Some studies had a mixture of validated scales in addition to scales that the author had created for the purpose of the study where it was not clear if they had been validated (e.g. Bauer, Redman, Bradley & Schiem; Sammons 2010; Schiem & Bauer, 2017). The majority of studies apart from Weyers, et al., (2009) and Bockting (2009) did not have a comparison or reference group with a non-transgender population. Potential for confounding and mediating variables were acknowledged in the majority of the studies, however, only some studies controlled for this (e.g. Nikkelen & Kreukels, 2018).

Data Analyses

A narrative synthesis was conducted to analyse the data based on established methods (Mays, Pope & Popay, 2005). Firstly, the key findings and initial themes relevant to the research questions were identified from the studies. Then relationships among the findings and initial themes were explored to find broader patterns of meaning in the data. These broader themes were then finalized through being reviewed and discussed with the project supervisor who provided guidance with further synthesis and considerations.

Results

Four main themes were identified, each containing subthemes, as discussed below.

1. Challenging cis-gender sexual assumptions

1.1 Completing Gender Confirming Treatment often not the goal

A key theme was challenging the assumption that completely medically transitioning was the majority of transgender individuals' goals. For example, Bockting et al (2009) noted that only 4% of transmen in their study had a phalloplasty, 40% desired one whilst 56% did not have any interest in pursuing them. Further, Schilt and Windsor (2014) in a large qualitative study of 74 transmen where 96% were taking testosterone hormone, 68% had chest surgery and 7% had genital surgery and only half

of the entire sample felt that their ideal body would include a penis. Similar findings were found in Williams' (2014) study of transmen where 8% had genital surgery with the majority (84%) feeling that genitalia did not define their gender. The reasons for not wanting to pursue genital surgery varied where some felt the limits in medical surgery meant they may not be satisfied with the results while others felt that testosterone alone was sufficient in feeling comfortable in their body. Though this was less frequently quantified in the transwomen studies, the majority of transwomen had hormone therapy with the minority having a vaginoplasty (e.g. Rosenburg; Mendelson, 2016), with some desiring further surgery whilst others having no desire or no intention of genital surgery (e.g. Nikkelen, Baudewijintje & Kreukels, 2018; Mendelson, 2016; Rosenburg, 2019; Schiem & Bauer, 2017).

1.2 Shift in sexual desires, emotions, practices and the concept of sex

Many of the studies documented changes in sexual preferences, desires and practices after transitioning. In line with previous research, the majority of the studies found that for transmen their sexual desire increased on hormones (Bockting, 2009; Doorduiun & van Berlo, 2014, Williams 2013, Brown, 2010). For transwomen this was more complex where some studies found a decrease (Doorduin & van Berlo, 2014) and others related more to a change in sexual preferences and practices. An increase in female hormones often resulted in transwomen being unable to sustain an erection, however, this was often not viewed as problematic and orgasms were no longer viewed as the goal with pleasure achieved through different methods and in different erogenous zones rather than genitals (Mendelson, 2016; Rosenburg, 2019). For example, sex was less about penetration or genital contact and more about other acts of physical intimacy such as caressing and massaging (Mendelson, 2006; Rosenburg, 2019). This shift was attributed to the impact of hormone therapy and the understanding that for some participants that using their genitals would increase their body dysphoria.

Emotional changes were described in transwomen where some felt more connected to their emotions (Rosenburg, 2019) and more able to express themselves which improved communication between their partners which increased sexual satisfaction (Mendelson, 2006). The emotional changes were attributed to hormonal therapy or feeling more comfortable in their body. However, these could also be explained by the social expectations of female's emotional expressiveness.

Participants described re-naming genitals, for example, the impact of hormone therapy can result in the clitoris growing significantly and some transmen renaming this as their '*penis*' and referring to their vagina as a '*front hole.*' (Williams, 2013; Schilt & Windsor, 2014). Others had different views and felt that without a penis they were inadequate, and their vagina served as a reminder of their femininity. The complexity of this relationship with their natal sex organs then impacted sexual behaviours where some wanted to avoid certain areas where others were comfortable with using these areas sexually (Bockting, 2009; Doorduiun & van Berlo, 2014, Williams 2013, Brown, 2010; Schilt & Windsor, 2014).

2. Heteronormative and cis-gender impact on sexual experiences

2.1 Impact of Gender Roles

Another finding was the impact of gender role expectations on sexuality. Tree-McGrath (2018) described that transmen views on sexuality were affected by experiencing pressure to be perceived as masculine and encompass societies stereotypical views on manliness. Transmen who did not prescribe to strict stereotypical views around masculinity experienced different social stressors through people's judgements over them not having a prescribed visible gender. Williams (2013) reported for some transgender individuals they placed high importance in sexual interactions being conducted in a culturally defined way in order to reinforce their gender identity. Mendelson (2006) found a shift in gender role adherence where transwomen initially felt a pressure to be perceived as feminine and would find themselves strongly wanting to adhere to this feminine stereotype including sexually.

2.2 Negative impact of cis-genderism

Transgender individuals have negative experiences where others viewed them as a sexual fetish rather than a person (Riggs, von Doussa & Power, 2015; Lindroth, 2017; Riggs, von Doussa, 2017). Experience of being treated in this manner resulted in difficulties in romantic relationships (Riggs von Doussa, 2017). Lindroth's (2017) study documented that one third of trans individuals had been forced to have sex against their will and a third reported sexual coercion. This study documented that fear of being disrespected can lead to avoidance of sexual relationships. Similarly, Riggs (2015) found that anxiety over potential partner's responses and worries over potential discrimination led to avoiding romantic relations.

Bauer et al (2013) investigated transphobia violence where 36.1% reported verbal harassment and 16.9% reported sexual or physical assault. Though not statistically significant, Schiem and Bauer (2017) report that transphobic and physical assault were associated with sexual inactivity. Further research is required to examine this link; however, it is plausible that trans individuals may avoid sex in order to minimise risk of assault or/and due to the trauma of past assaults. It is also noteworthy that these authors found that childhood sexual abuse in transwomen was significantly higher than expected than cis-gender males at 37%. This could be due to having increased vulnerability as children due to their possible non-conformity.

3. Body Image

3.1 Body Dysphoria

Dissatisfaction with one's body due to it not being aligned with a person's gender and the subsequent negative impact on sexual experiences was a recurring theme. Bauer, Redman, Bradley and Schiem (2009) found that 57.4% of transmen had moderate or high levels of trans-related body image worries in sexual situations. Scheim and Bauer (2017) found that sexual inactivity in transwomen was associated with worries about trans-related body image in sexual situations.

Doorduin and van Berlo's (2014) qualitative study including both transmen and transwomen at varying stages of medical transition found all these individuals at some point had experienced gender dysphoria, although the intensity of the feeling and the stage at which it was most pertinent varied between participants. These feelings of gender incongruence would heighten during sexual experiences resulting in it negatively impacting on sexual pleasure. Half of the participants in this study discussed the impact of this on sexual arousal and orgasm. Participants described a complex range of emotions such as feeling pleasure mixed with disgust due to the pleasure being derived from a sexual organ that they did not wish they had. This could result in feeling a lack of control over their bodies. A method to manage the negative incongruent feelings was avoidance of sex or avoidance of certain parts of their body.

Platt and Bollard (2016) similarly describes body dysphoria impacting negatively on sexual relationships, even in those who had completed GCT. This is described through participants having ongoing insecurity regarding their bodies and feeling self-conscious at other's viewing their body. This dysphoria led a significant number of participants avoiding certain body parts in sexual relationships.

3.2 Body Satisfaction

Weyers et al., (2008), who investigated the psychological and sexual health of transwomen who had completed sex reassignment surgery six months prior, found that satisfaction with their body image was good and comparable to cis-females without sexual difficulties. Weyers (2008) also reported a relationship where higher levels of appearance satisfaction correlated with higher levels of sexual satisfaction, though the causality of this and any confounding variables were not established. Mendelson (2006) found that one reason transwomen attributed to increased sexual satisfaction was feeling more comfortable in their body.

Sammons (2010) examined body image and sexual pleasure pre and post SRS for transwomen and found that GCT improved body image and sexual pleasure. However, this questionnaire was administered post-surgery and involved participants retrospectively considering their pre-surgery body image and sexual pleasure. Further, the author does not consider other directions of causality or other mediating factors, for example, an increase in sexual pleasure through affirming sexual experiences having a positive impact on body image. The qualitative findings in this study discussed the theme where unhappiness with a person's body leads to avoidance of sexual activity, as found in Scheim and Bauer (2017) study.

Nikkelen, Baudewijintje and Kreukels (2018) examined the impact of psychological well-being and body satisfaction on sexual satisfaction on a large (n=576) sample of trans people. In this study they separated trans individuals into three groups, people who had no wish to receive any gender confirming treatment (GCT), i.e. no treatment desire (NTD), those who had an aspiration to receive GCT; unfulfilled treatment desire (UTD) and those who had received GCT and did not want any further treatment; fulfilled treatment desire (FTD). Body satisfaction was strongly related to sexual feelings and behaviour emphasising the important of body image on sexual experiences. Interestingly, whilst there was evidence to suggest that FTD had a positive impact on sexual feelings in transwomen this difference was not found between those with an UTD and FTD in transmen. Further, differences between the three groups disappeared when body satisfaction and psychological well-being was controlled suggesting these factors are more important than if a person has or has not received treatment or if they desire further treatment.

This study adds to the complexity of the area by emphasising that GCT does not always equate to body satisfaction and improved sexual satisfaction and people can

achieve these without any GCT. However, Schiem and Bauer (2017) study notes that genital surgery in transwomen had a significant effect in predicting sexual activity.

4. Relational impact

4.1 – Impact of being in a relationship on sexual satisfaction

Three of the studies focused on the experience of sexual relationships through the perspective of the partner of a transgender individual. Pfeffer's (2008) study ascertains the link between transmen's body dysphoria impacting negatively on the sexual relationship with their lesbian partners. A key theme for these lesbians was their trans partner's body dysphoria resulting in an avoidance of them wanting to engage in a sexual relationship with their partner. Some of the partners noted the impact of their relationship with their own body image as negatively impacted due to their trans partner being hypercritical with their own body. This was further compounded by their trans partners not engaging in sexual relationships through their own body image insecurities likely leading to their partners feeling rejected.

Brown's (2010) study emphasised the complexity of gender transitioning on the relationship where both negative and positive impacts on sexuality were found. Negative impacts were partners concerns over their ability to find their trans-partner sexually desirable as a transman and the impact of this on how they viewed their own sexual identity and orientation. A theme was that partners who had a previous trauma history impacted negatively on the sexual relations with their trans partners due to it triggering feelings of vulnerability. Nonetheless, the majority reported positive aspects of sexuality through feeling increased sexual satisfaction. Similarly, Joslin-Roher and Wheeler (2009) found the majority of partners had increased sexual satisfaction due to their partner's increased confidence and body satisfaction. However, trans individuals who were dissatisfied with their bodies had a negative impact on the sexual relationship. Areas of difficulty were also the change in sexual practices and preferences during sex if there was not adequate communication.

4.2 The role of self-acceptance

Regardless of what stage of medical transition a key importance for positive sexual experiences was the ability to accept their bodies (Bocking, 2009; Tree-Margrath, 2018; Lindroth, 2017; Schillt & Windsor, 2013), where lack of self-

acceptance leads to avoidance of romantic relationships (Riggs, von Doussa & Power, 2015). Further, the importance of acceptance from their sexual partners (Platt & Bollard, 2016) to facilitate acceptance with their own bodies.

Discussion

The vast majority of literature on transgender individuals has focused on the physical aspects of sexual functioning with minimal consideration of the impact of the psychological issues that may contribute to sexual functioning and satisfaction. This review has identified a range of complex issues that warrant consideration including body dysphoria, relational issues, impact of cis-genderism and the role of acceptance. It also has considered the limitations in the current conceptualisation of the concept of sexual dysfunction.

For transwomen who do not desire or have not yet completed genital surgery, oestrogen hormones can result in changes to erectile functioning and a decrease in the ability to orgasm, which is in line with the wider literature (e.g. Knezevich, Viereck, & Drincic, 2012). Further, this review notes that transmen and transwomen who have not had genital surgery may avoid using their genitals during sex due to discomfort or dysphoria in this area. Heterosexual and cis-gender assumptions would potentially view erectile dysfunction and genital avoidance as a "sexual dysfunction." Given that trans individuals may experience a shift in the concept of sex and consider other ways to achieve sexual satisfaction that have been outlined in this review, this suggests that exploring sexual functioning that fits with trans individual's goals for their own body and practice is paramount.

The high amount of trans-related body image concerns suggest that these could have a significant impact on sexual functioning despite the lack of research testing this empirically. Consideration of the cognitive models of sexual dysfunction, (e.g. McCabe, 2007; Barlow, 1984) it is highly plausible that increased focus on the body leads to complex emotions including shame and anxiety which could decrease sexual arousal and sexual desire. This fits with Barlow and Beck (1984) theory where those who are experiencing sexual dysfunction have increased anxiety, reduced perception of control and increased distractibility. However, Barlow's studies were based on heterosexual males with erectile dysfunction problems. As demonstrated from the findings in this review, sexual desires and practices shift with transition where sexual experiences may

not include penetration for both transmen and transwomen, however, the importance of the ability to be sexually aroused remains.

There is an added complexity of a transgender person's relationship with their body where there can be high ambivalence over a body part that gives pleasure whilst also resulting in feelings of gender dysphoria. This could lead to a reduced perception of control over their body's physical reactions to sexual stimuli and from their partner's touches as described in Doorduin and van Berlo (2014); this is in line with the cognitive theories in that this could increase the risk of sexual dysfunction.

Sanchez & Kiefer (2007) investigated the link between body image worries and sexual experiences in heterosexuals. Their theoretical model proposed that body shame could impact on sexual arousal, orgasm difficulty and sexual pleasure directly or that body shame could impact on these due to increased self-consciousness. However, the evidence for this model is cross-sectional so while it is assumed shame impacts on self-consciousness and therefore arousal, causality is not inferred and it could be possible that experiencing sexual dysfunction results in increased body concerns and shame. However, previous research has documented the link between shame leading to reduced sexual satisfaction and sexual difficulties (Fredrickson & Roberts, 1997; Roberts & Gettman, 2004). Future research should examine the relationship between shame, self-consciousness and sexual arousal, pleasure and orgasms with transgender populations.

Objectification theory (Fredrickson & Roberts, 1997) refers to the high sociocultural emphasis on female appearance which results in self-objectification where women view their value in terms of their physical appearance leading to self-monitoring. The negative impact of self-objectification is well documented empirically with studies finding increased body shame, self-consciousness (e.g. Gapinski, 2003) and anxiety (e.g. Calogero, 2004). Objectification theory fits with the above research from Barlow & Beck (1989) and Sanchez & Kiefer (2007) which find negative self-focus hindering sexual arousal. Objectification theory is relevant when considering that a finding in this review was trans individuals experiences of being viewed as a sexual fetish object. The sexualisation of those identifying as trans has been well documented in the wider literature (Espineira, 2016). This links to the finding of the reports of sexual and transphobic verbal and physical assaults documented in this review. Further, despite progress, transphobia, and stigma are still highly apparent in society (Walch, Ngamake, Francisco, Stitt, & Shingle, 2012). Being objectified will likely have a significant

impact on willingness to engage in sexual encounters and subsequent sexual experiences and satisfaction.

The results from this review addresses some of the factors in McCabe's (2007) holistic model of sexual dysfunction which describe the importance of belief systems in the family and values associated with intimacy, gender and sexuality. Identifying as transgender may be viewed as a conflict of values and a societal taboo within the family due to conflicting with traditional ideas of gender and sexuality that could lead to an increased risk of sexual dysfunction. A recent study investigated the impact of the sociocultural context on sexual desire in women who identified as bisexual, lesbian and heterosexual (Rosenkrantz & Mark, 2018). They found that minority stress, gender expectations and their sexuality being viewed as a taboo all impacted negatively on sexual desire. Minority stress refers to the stressors that sexual minority individuals face which impact on health and well-being (Meyers, 2003). These themes have been demonstrated to be present for transgender individuals, thus it could be postulated that these all have the potential to impact on sexual desire.

Avoidance of sexual activity was a thread that ran through the majority of the studies in this review and often attributed to body dysphoria and lack of acceptance of self and from others. However, some trans individuals may be sexually inactive due to it not being a focus or a priority. Sex is culturally defined as important though this is on a continuum with some people placing little importance and may identify as asexual (Riggs et al, 2017).

Limitations

A limitation of the review has been operationalising a psychological factor that impacts on sexual satisfaction. There are a huge number of psychological variables that have the potential to impact on sexual dysfunction and satisfaction that was beyond the scope of the review to examine, for example, general mental health, culture, abuse etc. This review, therefore, focused on studies examining sexual experiences in transgender individuals. As there is so little on psychological considerations in sexual satisfaction in trans populations that the search criteria was kept broad in order to capture possible influences that may not be relevant in cis-gender populations. The CASP was used to evaluate the quality of the articles, however, it is recognised that this process is subjective. Further, the articles varied in quality, however, it was felt that they all made valuable contributions to answering the research question. Another limitation is that the

literature focused on people who identified with a gender which therefore would not have captured people who do not define themselves as fitting into a binary category.

Future Research

The majority of the studies did not separate participants on the basis of their level of medical transitioning and some studies combined participants regardless of which gender they have transitioned. This did not allow for a more nuanced consideration of these factors on sexual satisfaction. Future research should directly examine the impact of shame, gender dysphoria, body image worries and self-consciousness on sexual satisfaction, sexual arousal and orgasms. This could be achieved through longitudinal, single case experimental designs with transgender individuals to gain a detailed insight into the relationship between these factors and to help determine causality. Future research would also benefit from including a non-transgender reference group as a comparison to assess similarities and differences between sexual satisfaction and sexual functioning. Completing gender treatment was often not the goal for the majority of transgender individuals and many were able to achieve body acceptance without medically transitioning. Future research would therefore benefit from examining the factors that facilitate acceptance of a person's body in order to help reduce body dysphoria.

Clinical implications

This review has highlighted the complexity of contributing factors that may impact on sexual dysfunction and satisfaction for trans people. This suggests the importance of clinicians having increased awareness of the cultural and contextual factors such as cis-genderism, transphobia and relational factors that may impact on sexual dysfunction rather than focusing solely on cognitive theories of sexual dysfunction.

Clinicians working with trans individuals should have the knowledge and awareness of transgender people's experiences of intimacy in order to provide optimum care. The extent to which trans individuals desire to medically reassign varies considerably from no desire for GCT, with many choosing hormones alone and some completely medically transitioning. The reasons for this are also diverse with some achieving complete satisfaction without full GCT whereas others it may be due to the current medical and technological limitations that GCT currently has. There is a

pertinent need for clinicians to be aware of the sexual body image worries and gender dysphoria that many transgender individuals experience and the impact of this on sexual experiences. Clinicians should be aware that transgender people may re-name their genitalia and other body parts and should be mindful of their preferred terminology. The role of acceptance from both self and partner's along with satisfaction with one's body is crucial and appears to be critically important in allowing optimum sexual satisfaction. This indicates that couple therapy may be useful for some in finding ways to facilitate acceptance. Further, the high levels of body dysphoria that may result in increased shame could suggest that compassion focused therapies may be useful.

Conclusions

Sexual satisfaction and sexual functioning has been demonstrated to be influenced by an enormity of variables at the individual, interpersonal, cultural level, in addition to various socio-demographics (Sanchez-Fuentes, Santos-Iglesias & Sierra, 2013). This current review aimed to begin to expand the current conceptualisation of trans sexual functioning beyond the physical aspects in order to consider what trans-specific psychological sexual health needs may be. The review has identified that trans people may be at an increased risk of sexual difficulties due to the increased complexity of body dysphoria leading to increased levels of shame, the negative impact of cis-genderism and difficulty of acceptance from self and others.

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University of Bath

Doctorate in Clinical Psychology

Service Improvement Project

Age Inclusive Compassion Focused Therapy: A Pilot Group Evaluation

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Abstract

Objectives. This study aimed to evaluate and provide recommendations to improve the effectiveness of an age inclusive Compassion Focused Therapy (CFT) group in secondary mental health services for participants experiencing a range of mental health difficulties. Of particular interest was the acceptability and impact of having a wide range of ages in such a group.

Methods. The study employed a mixed methods design. Validated self-report questionnaires were administered before and after the group intervention and qualitative semi-structured interviews were conducted with six group participants.

Results. There was a significant increase in ratings on the Self-Compassion Scale (SCS) and Mindful Attention Awareness Scale (MAAS), a significant decrease in the depression subscale within the Depression and Anxiety Stress Scale (DASS) and a significant reduction in the risk subscale of the Clinical Outcome in Routine Evaluation (CORE). No significant differences were found on the overall scores and other subscales of the CORE and the DASS. Thematic analysis of the qualitative data identified four main themes; "*Connection with others*", "*Experience of a diverse age range", "Group as a secure space*" and "*New strategies and tools"*.

Conclusions. This study provides preliminary evidence that an age inclusive CFT group is well received and has a beneficial impact for participants, with particular positivity gained through compassionately connecting with others. The range of ages was appreciated and appeared to have therapeutic benefits, although awareness of differing age-related needs is important. Limitations, recommendations for improvement and future research are discussed.

Introduction

Compassion as a therapeutic resource

Shame and self-criticism underpin a number of psychological difficulties and can be viewed as trans-diagnostic in that they contribute to accentuating and maintaining a range of mental health problems (Gilbert, 2009). Additionally, high levels of self-criticism can limit the effectiveness of therapy (Gilbert & Irons, 2005). To address these issues, there has been an increased focus on cultivating compassion in psychotherapy research. Compassion can be defined as, *'the sensitivity to suffering in self and others, with a commitment to try to alleviate and prevent it'* (Gilbert, 2014, p14). A substantial amount of research has documented the beneficial effects of compassion on well-being (Macbeth & Gumley, 2012; Crocker & Canevello, 2012; Rockcliff, Gilbert, McEwan, Lightman & Glover, 2008).

There are a range of compassion-based psychological interventions with empirical support. A recent meta-analysis examining 21 randomly controlled trials of compassion-based psychological interventions over the last 12 years found significant between group differences on self-report measures of compassion, self-compassion, mindfulness, anxiety, depression, psychological distress and well-being (Kirby, Tellegan & Steindl, 2017). The most evaluated of these is Compassion Focused Therapy (CFT), developed by Paul Gilbert. CFT draws its theoretical underpinnings from evolutionary psychology, attachment theory, neuroscience and social psychology (Gilbert, 2009).

The CFT model postulates that accessing affiliative emotions is key in regulating threat-based emotions (Gilbert, 2009). People who have experienced difficult early life experiences, including trauma or neglect, may be more attuned to threat based emotions than positive, affiliative emotions; thus increasing their susceptibility to psychological difficulties. Three types of affect regulation systems are described in CFT (Gilbert, 2009). The threat-focused system focuses on self-protection and safety seeking and produces emotions such as anxiety, anger and disgust. The incentive and resource focused system motivates, guides and encourages us and produces excitement, drive and vitality. Finally, the affiliative system focuses on soothing, safeness and kindness and is associated with contented and connected emotions. The aim of CFT is to enhance the affiliative system which will in turn improve regulation of the threat-focused system, resulting in improved psychological well-being.

CFT is a relatively new therapeutic approach with a growing evidence base. Leaviss and Uttley (2015) conducted a systematic review of CFT interventions which included 14 studies and found that it had potential as an intervention for mood problems, especially for clients high in self-criticism; however, before it could be considered evidence based, a higher standard of research studies was required. Within this review, seven of the studies were CFT groups with clinical participants experiencing a range of severe and complex mental health problems including psychosis, depression, personality disorder and eating disorders. Overall, these groups had a positive impact, including significant improvements on a variety of outcome measures including an increase in self-compassion and a decrease in depression, anxiety and shame (e.g. Judge, Cleghorn, McEwan & Gilbert, 2012; Gilbert & Proctor, 2006.)

Six out of seven of these groups reported participants' age which collectively ranged from 18-62 years, with the majority of groups having a mean age of participants in their twenties, thirties and forties (Braehler, et al., 2013; Gilbert & Irons, 2004; Gilbert & Proctor, 2006; Laithwaite, O'Hanlon, Collins, Doyle, Abraham & Gumley, 2009; Lucre & Corten, 2013 & Judge et al, 2012). Significantly, none of these groups included participants from an older adult population.

Older Adults and Compassion

The limited evidence for CFT with older adults is particularly significant given that people are living longer than ever which is often accompanied by numerous physical, cognitive and social changes (Allen, Goldwasser & Leary, 2012). Older adults have increased likelihood of experiencing multiple losses, dependency on others and reduced ability to engage in activities which can negatively impact psychological well-being and quality of life. In those who are vulnerable, the impact of these additional stressors may increase the likelihood of self-criticism and shame (Mirowsky & Ross, 1992); therefore, the ability to cultivate compassion is important in this age group.

Although the majority of compassion literature has focused on working age adults, limited research has investigated compassion in older adults with encouraging results: Allen et al., (2012) found that older adults with poorer physical health who were higher in self-compassion reported greater subjective well-being compared to those with lower self-compassion. Further, Phillips and Ferguson (2013) found that self-compassion was positively associated with meaning in life, ego integrity and positive affect and negatively associated with negative affect. These studies suggest that a

compassion focused therapeutic intervention could prove to have positive benefits in older adults and warrants further study.

Age Inclusive CFT

There is increasing evidence to suggest that older adults experience negative attitudes, stereotypes and behaviour including discrimination in many domains (McCann & Giles, 2002; Richeson & Shelton, 2006). CFT theory suggests that due to our complex brains, such negative stereotypes and behaviour might lead to threat based '*loops*' between the highly evolved '*new brain'* which can plan, ruminate and problem-solve and the '*old brain'* which is threat-based, emotionally driven and has desires for status and social position (Gilbert, 2014). CFT proposes that such threat-based '*loops*' might be remediated through the emphasis of a common humanity which reduces the notion of '*them and us.'* Consistent with this proposal, there is some evidence to suggest that intergenerational contact can help attenuate age-related stigma and subsequent ageist negative behaviour (Cummings, 2002). There is therefore a strong rationale for adopting an age inclusive approach towards delivering CFT and it would be expected that the approach might serve to reduce any negative stereotypes towards older adults and increase people's ability to focus on similarities rather than differences.

Aims of the Study

The aim of this study is to evaluate and improve the effectiveness of an age inclusive Compassionate Minds (CM) group which is a trans-diagnostic group based on Compassion Focused Therapy (CFT). The CM group has been facilitated for working age adults accessing secondary mental health services since 2008 within the 2gether Trust in Gloucestershire. Since 2015 the group has been piloted to include participants from both working age (WA) and older adult (OA) secondary mental health services of 2Gether Trust.

The aims of this study are two-fold. Firstly, CFT is a relatively new therapeutic approach and there is a need for further research to investigate the effectiveness of this therapy in improving psychological well-being. In particular, there is limited evidence of this approach in an older adult population and within the context of an age inclusive group, so this study will make a contribution to this literature. Investigation of effectiveness will be achieved through quantitative and qualitative methods; measuring the difference in pre and post group outcome measures and conducting interviews

which will include investigation into both group content and process. This exploration will help determine the most helpful and unhelpful aspects of the group which can then be used to modify future groups to increase their effectiveness.

Secondly, this study will provide evidence to help determine if delivering age inclusive groups is a feasible and effective option. Significantly, there could be psychological benefits through having a diverse age range group through increasing understanding and awareness of others' difficulties who are at a different developmental stage, reducing negative attitudes people may have of different age groups. There are also likely to be practical implications to consider when delivering age inclusive groups. A detailed examination of the experiences of an age inclusive group will therefore allow the service to consider if other therapeutic groups could benefit from a diverse age range and how best to implement these.

Referral Pathway

Participants were generally referred into the group by a member of the WA or OA mental health teams. They were then assessed by the group facilitators to ensure informed consent and suitability for the group.

Structure of the CM group

The age inclusive groups were facilitated by two experienced clinical psychologists who had both attended a 2-day CFT Workshop with Dr Deborah Lee and a 3-day CFT retreat with Professor Paul Gilbert. Both received supervision from a clinical psychologist experienced in working with the CFT model throughout each group. Each group had approximately 6-10 members. The groups lasted for 20 sessions, mainly on a weekly basis but with some breaks in the programme. Each session lasted for two and a half hours, with a coffee break. Halfway through the group programmes, each member was invited to meet with a facilitator to work on an individualised formulation. The group comprised of a number of interventions and specific exercises. See Table 1 for a description of the areas covered.

Table 2.1:
Description of topics in the CFT group

Topics covered in the CM Group
Mindfulness
Soothing rhythm breathing
"Three circles" model of emotional systems
Understanding our "tricky brains"
Understanding compassion
Understanding self-criticism
Compassionate mind training (CMT) – experiential exercises designed to access the soothing affiliative system and develop an inner compassionate voice
Personal formulations developed in an individual session with facilitators halfway through the programme
Compassionate letter writing
Relapse prevention

Method

Study Design

This study utilized a mixed method design combining qualitative interviews and quantitative self-report questionnaires to evaluate the impact of the CM group.

Quantitative Design

The age inclusive group has been completed with four different cohorts with a total of 23 participants; 12 from working age services and 11 from later life services with an age range from 32-82 years-old. Quantitative data was gathered from participants prior to commencement of the group, once or twice during the group, during the final group session and at three months follow-up. The facilitators would administer the measures to the participants and they were completed anonymously before the start of that group session. The quantitative measures were collated and quantitatively analysed using descriptive and inferential statistics to evaluate the overall effectiveness of this group compared to the current literature for other CFT groups.

Measures

The Self-Compassion Scale (Neff, 2003)

This scale measures self-compassion and has demonstrated good psychometric properties including being a theoretically good measure of self-compassion with

evidence of reliability and validity (Neff, 2003). This scale has been implemented in an older adult population with high internal reliability (Allen, et al., 2012).

Mindful Attention Awareness Scale (Brown & Ryan, 2003)

This 15-item scale assesses an awareness of what is occurring in the present which is a core characteristic of mindfulness. The scale has demonstrated good validity and reliability (Brown & Ryan, 2003). This scale has also been used successfully in older adult populations (e.g. Raes, Bruyneel, Loeys, Moerkerke & De Raedt, 2015).

CORE-34 (Evans, 2002)

This is a 34-item self-report scale examining domains of subjective well-being, symptoms, function and risk. The CORE-34 has demonstrated good reliability and validity with good sensitivity to change (Evans, 2002). The CORE has demonstrated to have good reliability in an older adult population when using the overall average, however, this reliability is reduced when examining specific domains, (Barkham, Culverwell, Spindler & Twigg, 2005).

Depression Anxiety and Stress Scale (Lovibond & Lovibond, 1995)

This is a 42-item self-report scale examining depression, anxiety and stress and has been demonstrated to be a reliable and valid measure (Crawford & Henry, 2010). The DASS-21 has been investigated in older adults which found good internal consistency, excellent convergent validity, and good discriminative validity.

Qualitative Design

Participants

Participants were five women and one man who had all completed a CM Group and they ranged in age from 34-69 years old. Five of the participants were from the same group cohort and one participant was from a different group cohort. Three of the participants were considered in the WA range (18-64) and three were considered OA (over 65 years old). Participants were all white British with English as their first language. All were in secondary mental health services and experienced a wide range of psychological difficulties.

Interviews

The interview questions were developed through firstly examining feedback forms that group participants completed on their final group session or shortly afterwards. These feedback forms asked questions on what people found helpful, unhelpful, the structure, length and age range of the group, experiences of being in a group and anything they would like changed. The researcher collaborated with the two group facilitators and a previous member of a CM group (who did not participate in the research) to discuss key areas of interest to the service that would be useful to explore further in individual interviews. This resulted in the following research questions for the qualitative component of the study being formulated:

1. What are participants' experiences of being in a mixed age range group?
2. What are the specific elements of the group that participants find most helpful and unhelpful?
3. What are participant's experiences of having an individual session to work on their formulation of their difficulties?

From these research questions, a semi-structured interview (see appendix 1) was devised which incorporated specific questions and optional follow-up questions whilst also allowing the researcher freedom to ask unplanned follow-up questions if they felt pertinent or relevant to the study's aims.

The interviews typically lasted between 20-50 minutes and were audio recorded. The researcher did not know any of the participants personally or professionally.

Procedure

The researcher attended a follow-up group and participants were informed about the project and given a participant information sheet. Those who were interested provided contact details and were contacted a week after receiving the participant information sheet to allow them time to reflect on participation. The interview took place at their local mental health clinic or in their own home, depending on preference. Written and verbal informed consent was obtained prior to commencing and participants were given a £5 voucher for taking part. Full ethical approval was obtained from University of Bath

Psychology Department Ethics Committee (Ethics: 17-217) and the Research & Development Team of 2gether Trust (Ref: 17/030/2gt/SE).

Quantitative Data Analysis and Results

Descriptive statistics (median and range) and statistical tests were generated using SPSS version 24. Due to the small sample size and the data violating the assumptions of normality, the non-parametric Wilcoxon signed rank test was used to compare the pre and post data. Due to incomplete data, the questionnaires from the middle of the group and at three-month follow-up were not included.

The data analysis for the pre and post measures is depicted in Table 4. This analysis revealed a significant increase in the SCS ($z = -2.663$, $p < 0.008$), MAAS ($z = -2.663$, $p < 0.01$) and a significant decrease in the Depression subscale ($z = -2.280$, $p < 0.023$) within the DASS and Risk subscale ($z = -2.020$, $p < 0.043$) within the CORE. The overall score and other subscales within the CORE (wellbeing, symptoms and functioning) and DASS (anxiety and stress subscales) did not find any significant differences.

Table 2.2:

Results of the analysis of the pre and post measures

Collation of 4 cohorts available data sets	**N**	**Pre M (SD)**	**Post M (SD)**	***Z***	**Wilcoxon Significance (p)**
SCS Median Range	22	2.00 (1.31-3.48)	2.71 (1.12- 3.29)	-2.663	.008*
MAAS Median Range	23	3.4 (2.13 – 4.38)	3.93 (2.33-5.27	-3.179	.001*
DASS:					
Depression Median Range	12	28.5 (0-42)	18.5 (5-42)	-2.280	.023*
Anxiety Median Range	12	12.5 (6-40)	8.5 (3-40)	-1.156	.248
Stress	12				

Median Range		24 (6-37)	14.5 (6-36)	-1.808	.071
CORE - all items Median Range	10	1.64 (1.15-2.68)	1.22 (0.76-2.59)	-1.478	.139
CORE -Wellbeing Median Range	10	2.5 (1.5-3.5)	2 (1-4)	-1.404	.160
CORE-Symptoms Median Range	10	2.33 (1.33-3.25)	1.67 (1.08-3.92)	-0.890	.373
CORE-Functioning Median Range	10	1.63 (1.25-1.75)	1.38 (0.75-2.33)	-1.305	.192
CORE – Risk Median Range	10	0.17 (0.00-1.00)	0.00 (0.00-0.50)	-2.020	.043*

Note. *p<.05

Qualitative Data Analysis and Results

All interviews were audio recorded and transcribed verbatim. Thematic analysis was used to analyse the data using Braun and Clark's (2006) approach. This consisted of firstly becoming familiar with the data through reading and re-reading the transcribed interviews. Secondly, the entire data set was coded and then the codes collated with the relevant data extracts. Thirdly, the codes and collated data were examined to identify broad patterns of meaning in the data to identify potential themes. Fourthly, the themes were checked against the data set and finally they were defined and named. An independent researcher coded a subset of the data and discussed their interpretation of the data with the primary researcher to help refine the final themes.

The researcher approached the qualitative data from a critical realist perspective which assumes that people's experiences and perspectives can be reflected through their language whilst recognising this is mediated both culturally and by the participant and

researchers' interpretation of the events. The researcher had minimal experience or training of working in CFT.

Four main themes were derived and are shown in Table 3 (see Appendix for Thematic Map)

Table 2.3:
Themes identified from participant interviews

Main Themes	Sub-Themes
Connection with others	Cultivating empathy and compassion
	Shared solidarity in suffering
	Positive emotion towards the group
	Fear of judgement
The experience of a diverse age	Appreciation of a mixed age range group
	Universality of distress
	Differing age-related needs
Group as a secure space	Good structure
	Supportive group
	Desire for continuation of group relationship
New strategies and tools	Activating soothing system
	Awareness of emotions
	Ability to formulate difficulties
	Individuality of exercises

1. Connection with others

1.1 Cultivating empathy and compassion

A strong theme was that the group fostered an environment where people developed compassion and empathy for each other:

"As time went on you got to know the group you also felt concern for each of the other people in the group." (P3; OA)

"It was lovely being able to sort of empathise with people, more having heard of what they've been through, sort of like week by week." (P5; WA).

1.2 Positive emotions towards the group

All of the participants reported experiencing positive emotions towards the group, many discussed looking forward to attending each week:

"I'd sort of wake up and think, oh great I got the group today will get to see all the people there, so I've very much enjoyed being in the group." (P6; OA).

1.3 Shared solidarity in suffering

Participants spoke fondly of having a shared sense of belonging through all having experienced psychological difficulties:

"It was nice having other people around who I didn't feel, well you're okay and I'm not so I really shouldn't talk to you, cos you'll pick up on my not okayness. It was kinda like, well we're all kind of in this group together not being very ok with it all and trying very hard. So, I think the group was helpful in that (P5; WA).

1.4 Fears of judgement

Many of the participants expressed initial concerns over how they presented themselves in the group. Some worried that others would think less of them through self-disclosure and feared showing vulnerability;

"Don't want to throw your hat in the ring, you know" (P6; OA).

One participant was concerned they were too talkative while another found it difficult to share with the group and feared their shyness would be viewed negatively:

"I hope I wasn't a problem to other people" (P4; WA).

1.5 Development of interpersonal skills and emotional boundaries

A key aspect of the group for some participants was learning not to take on others' problems which was something that they previously had struggled with:

So, the group really benefitted me in that way, I kind of learnt not to take on other people's problems really, so that was quite a big thing for me (P4; WA).

Learning to reconnect with people and develop interpersonal skills appeared to be key for a couple of participants:

The group is good to try to interact with others, I think that's part of what goes wrong with people their own ability to connect it comes down to that a lot, so yeah (P5; WA).

2. The impact of diverse ages

2.1 Appreciation of a mixed age range group

All participants spoke positively of appreciating the differing age range of the group members.

"It was a just nice size group and the diversity of people and the age, that's always good." (P2; WA)

2.2 Universality of distress

Having a range of ages helped participants recognise that psychological distress can happen to anyone at any point in their life.

"Everybody in some stage of their life, wherever you be younger, middle age, older, people have problems, people have mental health problems." (P2; WA)

"Definitely yes everyone was nice, and it helped me to sort of see that you know that it can affect anyone at any age and I think it's just good to have a good mix of people really." (P4; WA)

This appeared to be quite powerful in both age groups where they recognised the plight that different generations face:

"Yes, what some younger people are carrying, which I know I had to carry and thankfully they are getting help again." (P6; OA).

2.3 Differing age-related needs

One of the older adults reported difficulty hearing the group members and facilitators and would have benefitted from people speaking louder. A working age (WA) participant felt that hearing was a difficulty for the older adults in the group:

"Those who were a bit older...they couldn't necessarily hear me very well…I think everybody needed to speak up for the benefit of everybody else kinda thing." (P4; WA)

One OA reported that they didn't approve of people swearing and would have appreciated group rules over this.
"I find it offensive" (P6; OA)

Two of the WA participants felt that some of the older adults required further time to consolidate the learning from the group and had difficulty recalling as much from previous sessions compared with younger people in the group;
"My perception was maybe the people were a bit older, I don't know how to say this without being rude, maybe they needed a bit more time for the therapy, a couple of them, for the therapy to work." (P4; WA).

3 Group as a secure space

A strong theme was that the group fostered an environment which was supportive, containing and structured.

3.1 Group as supportive

"I think when you are going through and you are going through things in life I did feel supportive it was a nice little safety net, I could go there for a couple of hours and id be alright"(P2; WA).
"We are all there to be helped and we helped each other we were a supportive group, we kind of supported each other which is always good. Yeah it was a nice group." (P4;WA)

3.2 Good structure

The majority of the participants spoke highly of the structure of the group where the facilitators were mindful of the needs of the group, with a good mix of learning and discussion.;
"It was structured, although you didn't know it was being structured in that way, it was good how they did it, the two of them complimented each other and um yeah it worked well." (P2; WA)

3.3 Desire for continuation of the group relationship

The majority of the members would have valued more follow-up sessions. Some felt this would help formulate their difficulties better:

"I know money, time, this that and the other but it probably been nice to have a couple of sessions as a refresher, so you can put it all into context." (P2; WA).

Others felt it would have helped with sharing of resources and continued learning,
"I think further groups with someone not, you know, someone knowledgeable leading the group, would take people, you know, further on their path really" (P3; OA).
Many of the group members would have preferred the group to be increased its spacing of latter sessions to avoid an abrupt finish.
"You got quite attached." (P3; OA).

"Maybe do twenty weeks and then leave it for a month and have a few more meetings perhaps even five or ten so you didn't suddenly feel so abandoned" (P1; OA).

4.1 New strategies, concepts and tools

4.1 Activation of the soothing system

The majority of participants discussed enjoying creating an imagery of a safe and happy space. Almost all participants emphasised how helpful the soothing, rhythm breathing has been;
"The breathing is really quite useful. I mean it doesn't cure anything; it's not a wonder cure, but it definitely helped." (P1; OA).

4.2 Awareness of emotion

Participants in the group discussed an enlightened understanding of emotions;
"I suppose the biggest thing is that nothing really lasts forever. You know you might feel absolutely down in the dumps one day, or angry or felt rejected, or any negative emotion but it won't last forever." (P1; OA).

I'm much more aware of my, prior to this mood, the word mood didn't evoke any understanding and some intellectual understanding of it but nothing in my body, emotional yea? Now mood and feelings resonate in me." (P3; OA).

4.3 Individuality in exercises

Though participants found the majority of the content helpful there was individual variation where some people disliked certain exercises and one individual found an exercise emotionally difficult.

"I'd find my mind drifting in that because I felt like damned and cursed so no one's peaceful well-wishing would even touch that" (P5; WA).

4.4 Ability to formulate difficulties

Through having an individual session, some of the participants reported being able to understand the theory in context of their own lives.

"That was useful because it allowed me to place what's happened to me and to build up some goals for the future" (P4; WA).

Some felt that longer and additional individual sessions would allow them to build on this further.

Discussion

This study aimed to evaluate the effectiveness of a mixed age range CFT group in secondary mental health services in order to make improvements. The overall results suggest that this is a beneficial group that has had a positive impact on participants. The quantitative results demonstrate significant increases in self-compassion and mindfulness attention awareness, however, the majority of the domains within the mental health measures (DASS & CORE) did not reach significance though all domains showed a reduction in symptoms. The lack of significant change on the majority of CORE domains and anxiety and stress components of the DASS domains is dissimilar to some of the CFT group literature where significant positive changes on mental health measures were achieved (e.g. Lucre & Corten, 2013; Judge, et al. 2013). One explanation could be that due to the DASS being replaced with the CORE these questionnaires had roughly half the sample size in comparison with the SCS and MAAS which could contribute to the lack of statistical significance due to reduced power.

Despite the consistent lack of statistical change on the mental health measures, the qualitative results suggest that the group had a powerful impact on its members. A crucial aspect of the experience of the group was connection with others. This is highly

important as creating a group context which cultivates compassion and empathy towards its members enables individuals to feel reduced shame, increased validation and to feel soothed (Bates, 2005). Participants described the group as a positive experience, where they would look forward to attending each week. CFT focuses on the importance of engaging in experiences which will help activate the affiliative/soothing system and attending a group which experiences such positive cohesiveness will activate this system. Participants also expressed a sense of belonging through sharing difficulties; the CM group allowed the opportunity for affiliative sharing where people share their own stories and listen to others which results in the normalisation of their suffering. This in turn helps people feel less alone and increases connectedness with others resulting in reduced feelings of shame (Bates, 2005).

Significantly, results from the qualitative analysis demonstrated that the experience of being in a mixed age range was positively appreciated by all group members and contributed to people's ability to recognise the ubiquitous nature of psychological distress. This is significant as a key aspect of the CFT is promoting the idea of a common humanity to reduce the idea of '*them and us*.' This may have been particularly important for older adults where due to cohort beliefs may have felt increased stigma and alienation at experiencing mental health difficulties (Palinkas Criado & Fuentes, 2007.) Previous research has found that intergenerational contact reduces ageist stigma (Cummings, 2000) and it could be speculated that the sub-themes derived in this study including "*the universality of distress*", "*shared solidarity in suffering"* and "*cultivating empathy and compassion*" suggest some mechanisms that may play an important role in this. Further exploration of the role of these themes within intergenerational contexts is a possible direction for future research.

Participants valued the experience of learning new strategies and tools to activate their soothing system and relate to their difficulties differently. There was a high desire for continuation of the group experience with the focus on increased learning of strategies and ways of continuing implementing them into people's lifestyles. It is possible that increased learning and integration of these activities into people's lifestyles through additional follow-up groups could lead to further positive benefits on their psychological well-being.

Based on the findings, the recommendations for the clients and service were as follows:

Table: 2.4
Recommendation for service improvements

1. Mixed-age range recommendations
Ensure that all participants are able to able to hear the facilitators and group members. This could be achieved by enquiring about hearing difficulties in the initial referral assessment. Practical strategies to attenuate this could be asking everyone to speak louder and people with hearing loss to sit closer to the facilitators during group exercises.
Considering cohort beliefs when creating group rules, for example, recognising that some people, possibly OA more so, may not be comfortable with swearing so setting up rules to ensure all participants feel comfortable with the group language.
Recognising that cognitive capabilities will vary amongst age and being mindful to pitch the theoretical teaching at a level suitable for all ages and a range of abilities.
Making use of memory aids to improve recall of material learnt, for example, simplified summaries of each session
Being aware that due to cohort beliefs WA participants may be wary of disclosing information that they may deem upsetting for older adults to hear due to the perception that they will be less familiar with such issues, for example, issues around self-harm.
2. Individual Formulation Session Recommendations
Considering increasing the number of individual formulation sessions to further consolidate people's ability to place the learning in context
Having reminders of the group content during the formulation session to aid people's memories of the sessions
Consider having a longer amount of time dedicated to this session
Consider providing handouts of the outcome of the formulation session to aid participants' memory and understanding.
3. Content Recommendations
Be aware of the individuality of participants and how some exercises may provoke a strong negative reaction so having the option of another item to do during this time period may be helpful
The pragmatic exercises were powerful and fondly remembered, such as going on an outing together.
Provide advice to help people continue with the exercises once the group has finished.
4. Follow-up group Recommendations
To reduce the sense of loss and sadness when the group ends, it may be helpful to gradually increase the time period of the last few sessions
An increased amount of follow-up sessions may be helpful for improving adherence to the model and allowing participants to place it successfully into context.
Guidance to further resources and groups in the community would help with continuation of psychological learning and continuation of connecting with others.
5. **Evaluation Recommendations**

Collecting frequent mental health measures can be time-consuming and arduous for both clients and staff which may explain the lack of complete data for the mid-group and 3-month follow-up. Focusing instead on collecting three-month follow-up data rather than mid-group data may help minimise the burden whilst gaining valuable data on the sustained effectiveness of the group.
6. Service Recommendations
Mixed-age range groups have been well-received with all members interviewed appreciating the diverse age range.
Consider having equity of access across other psychological therapy groups in the trust.

Feedback and Dissemination

The results and recommendations of this study were fed back to the older adult service lead. In response several recommendations were implemented; firstly, an extra 'follow-up' session has been included to allow a more gradual ending of the group. Secondly, a group of experts by experience are working with the service's social inclusion team on developing a community-based group for 'graduates' of the CM group which will allow people to continue their compassion focused skills on completion of the group. Thirdly, a review will be arranged to consider different measures to evaluate the group in order to capture the qualitative findings more effectively. Finally, the findings will be discussed with other service managers to consider how age inclusive groups could be considered more widely in the trust.

Limitations

The small number of participants means it is difficult to generalise the results to other groups or settings. It is also difficult to ascertain if data saturation was achieved. Further, five of the participants were from one cohort where as one participant was from a different cohort (P1). Each cohort undergoes a unique group relationship so ideally having all participants from one cohort would have been desired. However, having a participant from a different cohort who also had similar positive group experiences can also be viewed as a strength as it shows some generalisability. Due to lack of complete data it was not possible to include participants' questionnaire scores during mid-group and at a 3-month follow-up group.

Conclusions

In conclusion, this study aimed to evaluate a mixed age range CFT group for participants in secondary mental health care. The results provide preliminary evidence that the group is well received and has a beneficial impact on participants. The CFT group appeared to have a significant impact on both participants group experience of compassionately and positively connecting with others whilst learning strategies and skills to help them relate to their difficult experiences differently. Having a diverse range of ages appeared to enhance participants' understanding on the ubiquity of psychological distress helping normalise their own difficult experience resulting in increased self-compassion. These results also suggest that awareness of differing age-related needs is important in order for diverse age range groups to function at an optimal level. Further research adopting these mixed age range recommendations and further examining the utility of diverse age range groups are required.

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University of Bath

Doctorate in Clinical Psychology

Main Research Project

Exploring if Nostalgic Memories affect how People relate to their Dementia

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This Journal publishes a range of research in the area of Alzheimer's Disease therefore appeared appropriate journal to target

Abstract

Background: Examining the psychological impact of dementia includes understanding how it acts as an existential threat. A consequence of dementia being a threatening entity is that people can find it difficult to engage with their dementia diagnosis. Applying findings from Terror Management Theory and the Mnemic Neglect Effect to people with dementia has previously shown the role of nostalgic memories in boosting psychological resources, enabling assimilation of threatening, self-referent information about dementia.

Objectives: This current study extended previous research through investigating whether recalling a nostalgic memory, in comparison with an ordinary memory, enables people to engage with the implications, including emotional and practical consequences, of their dementia and reduces death anxiety, without an increase in negative affect.

Methods: Eighteen participants with mild dementia were randomised to a nostalgic or ordinary memory condition and completed questionnaires examining recognition of the implications of dementia on their life and death anxiety.

Results: Nostalgia did not significantly impact on the recognition of the implications of dementia or on death anxiety. There was no significant change in participants' affect throughout the study.

Conclusions: The small sample size means it is difficult to draw clear conclusions on the impact of nostalgia in this context. However, this study demonstrated that it is feasible to discuss these sensitive topics with people with mild dementia without causing an increase in negative affect. It also identified that the majority of the participants experienced moderate levels of death anxiety. Clinical implications and future research are discussed.

Introduction

Dementia is a clinical syndrome involving a progressive deterioration in cognitive functioning through neurodegenerative changes in the brain which impact on a person's daily functioning. There are many different types of dementia with the most common being Alzheimer's disease and vascular dementia. As these illnesses progress they impact on a wide range of abilities, leading to increased dependency (NICE, 2017).

The interactions between declining cognition, psychological and social factors mean that attempting to understand the concept of insight and awareness that a person has in relation to their dementia diagnosis is multi-faceted and complex (Clare, 2003). For example, a person's awareness can differ in relation to numerous areas including self-care, memory and language abilities (Vasterling, Seltzer, Foss & Vanderbrook, 1995). Further, research has demonstrated that there can be an implicit awareness of one's dementia despite an explicit awareness being absent (e.g. Beardsall, 1993). Conversely, others may demonstrate an explicit awareness of their difficulties caused by their dementia, whilst presenting as indifferent about these issues (Howarth & Saper, 2003).

Conceptualising dementia as an existential threat is one psychological factor that may contribute to a person's insight and awareness into their dementia diagnosis. For example, research has demonstrated that dementia represents a threat to a person's identity, personhood and well-being (Kitwood, 1990). Further, research has examined the threat of dementia on relationships (Browne & Shlosberg, 2002) and to the self (Sabat, 2005). A recent survey found that people feared developing dementia over any other health condition demonstrating the threat this disease evokes (YouGov Poll, 2014). Given that dementia represents a threat to identity, including self-functioning, it is important to examine how people may defend themselves against such threats, and what the clinical consequences of doing so might be.

Mnemic Neglect Effect in people with dementia

Preliminary experimental evidence for protecting the self from the threatening implications of a dementia diagnosis has been demonstrated through the Mnemic Neglect Effect (MNE) occurring for people with a dementia diagnosis (Cheston, Dodd, Christopher, Jones & Wildshcut, 2018). The MNE model explains how people protect themselves from threatening information in the form of feedback. In order to maintain a

positive self-concept (e.g. Baumeister, 1998; Sedikedes, Gaertner & Toguchi, 2003) the MNE model holds that information that is received about the self is evaluated and connected to knowledge about a person's self-concept. The model postulates that there are two stages for processing self-relevant feedback. The first stage evaluates the new information against a person's self-concept and if viewed as self-threatening the processing of the information is mainly constrained to this stage. If the information is not considered as self-threatening it will undergo a more elaborate processing in stage two. Consequently, the MNE model predicts that information that is highly threatening to the self will be recalled more poorly than the same information that relates to another person. This is the Mnemic Neglect Effect - the selective forgetting of self-relevant feedback that is highly threatening to the self.

Cheston, et al. (2018) applied the MNE paradigm to people with dementia and found that they displayed a MNE in response to self-threatening information about dementia. Participants were asked to recall statements about dementia that ranged from low to high threat and the statements were allocated to either a self-referent condition (e.g. "*The impact of your illness depends on your emotional resilience*") or other-referent condition (e.g. "*The impact of the illness depends on Chris' emotional resilience")*. The results showed no difference in recall of the least threatening statements. However, significantly more highly threatening statements were recalled in the other referent (about Chris) compared to the self-condition. These interactions disappeared for recognition demonstrating that it was a processing deficit rather than a memory deficit. This is relevant because it suggests a motivational bias where people protect themselves against threat to the self through selective forgetting of negative self-referent statements.

One potential clinical implication of demonstrating that people living with dementia experience the MNE for dementia-related information relates to the difficulties that some people can find in engaging with their dementia diagnosis. Lack of awareness and understanding of dementia is often assumed to be due to cognitive difficulties (Green, Goldstein, Sirockman & Green, 1993); however, there are also significant psychosocial factors that could work in ways to protect sense of identity (Clare, 2003). For example, the assimilation of problematic voices model (APV) of therapeutic change (Stiles, 2001) has been applied to the psychological aspects of dementia awareness (Cheston, 2013). The APV postulates that most experiences are easily assimilated into a person's self-concept; however, some experiences have such

threatening implications that this assimilation is resisted. Qualitative analysis of psychotherapeutic groups for people with dementia emphasise the psychological dilemma of accepting such a diagnosis, resulting in ambivalence over whether to approach or retreat from it (Cheston, 2013). The MNE, then, might reflect the operation of a psychological process similar to repression, whereby highly threatening information about dementia is more likely to be forgotten or pushed out of conscious awareness.

Nostalgia and the MNE

Previous research in non-clinical populations has demonstrated that the MNE can be eliminated by situational factors and individual differences (Hepper, Gramzow & Sedikidies, 2010), for example undergoing an ego-inflation prior to recall (Green, Sedikides & Gregg, 2008). A situational factor akin to ego-inflation that has been recently been investigated in people with dementia is nostalgic reminiscence. Nostalgia can be defined as a '*sentimental yearning for the past'* (New Oxford Dictionary, 1998). Research has shown that nostalgic reminiscence can bolster psychological resources in both non-clinical and more recently dementia populations (Routledge et al., 2011; Ismail, et al., 2018). Specifically, people with dementia who recalled a nostalgic memory (in comparison to an ordinary memory) had an increase in self-esteem, social connectedness, optimism and meaning in life (Ismail et al., 2018). This nostalgic paradigm was combined with the MNE paradigm, showing that recalling a nostalgic memory (in comparison to an ordinary memory) enabled increased recall of self-threatening statements about dementia thus eliminating the MNE (Ismail et al., 2018). This suggests that nostalgia, through boosting psychological resources, enabled people with dementia to engage with the self-threatening dementia statements.

The importance of nostalgia as a psychological resource can be understood in terms of terror management theory (TMT). At the heart of TMT lies the psychological conflict that humans face between having the instinct to live whilst having the self-awareness that death is inevitable. TMT postulates that the death anxiety that this conflict produces is managed by investing in cultural norms that enhance psychological resources including self-esteem, social connectedness, self-continuity and meaning of life. The function of these psychological resources is to buffer against death anxiety

caused by existential threat (Rosenblatt, Greenberg, Solomon, Pyszczynski & Lyon, 1989).

Nostalgia is potentially one such cultural norm that has been evidenced to boost psychological resources and reduce existential threat (e.g. Routledge, Arndt, Sedikides, & Wildschut, 2008; Sedikides & Wildschut, 2008). Juhul, Routledge, Arndt, Sedikides and Wildschut, (2010) measured trait nostalgia and manipulated mortality awareness (e.g. high mortality salience where participants contemplated their own death versus a control condition where they contemplated dental pain) and measured death anxiety. High trait nostalgia resulted in reduced death anxiety compared to low trait nostalgia in the high mortality salience condition. This suggests high levels of nostalgia offer protection against death anxiety.

Clinical Implications

The recent demonstration of the potential benefits of nostalgia for people with dementia may have clinical implications. Firstly, Reminiscence Therapy (RT) is a widely used intervention for people with dementia which involves discussing past experiences, events and activities with the aim of promoting well-being, sustaining social relationships, and stimulating cognitive activity. Qualitative research highlights the value that people with dementia and their carers assign to RT. However, the quantitative evidence for improving mood, cognition and well-being for people with dementia is inconclusive (Charlesworth et al., 2016; Woods et al, 2016). One possible reason for these inconclusive findings is the failure of RT to differentiate between ordinary past memories and nostalgic memories (Charlesworth & Wenborn, 2017). Consequently, for RT to maximise potential psychological benefits of reminiscence, it may require clearer focus on nostalgic, autobiographical memories.

Secondly, if nostalgia enables assimilation of self-threatening dementia information, this could point to ways to help people receive and understand the implications of their dementia diagnosis. There are many benefits for an individual to be able to engage with their dementia diagnosis at an early stage including allowing them to make important decisions about their future before any significant cognitive decline. Furthermore, greater awareness and ability to engage with dementia has positive associations with better therapeutic outcomes including cognitive rehabilitation (Clare, 2001) and reducing caregiver stress (De Bettignies, Mahurin, & Pirozzolo, 1990).

Thirdly, nostalgia may buffer against death anxiety in people with dementia. The social psychology literature has demonstrated that nostalgia buffers against death anxiety in a non-clinical population, however, this has not been demonstrated in a clinical population. Given that dementia is a life-limiting condition it is clinically relevant to investigate levels of death anxiety in this population and to investigate if nostalgic memories have the potential to reduce death anxiety in people with dementia.

Aims of the current study

It has been demonstrated that people with dementia are less likely to recall negative, self-referent dementia related information and that nostalgia attenuates this threat enabling greater recall. It has been speculated that these manipulations represent an experimental analogue of the psychological processes underlying the clinical phenomena of repression or lack of awareness of a dementia diagnosis (Cheston et al, 2018; Ismail et al, 2018). However, this claim has yet to be fully investigated.

The current study therefore aimed to investigate if inducing nostalgia, thus increasing psychological resources, can result in a person being able to acknowledge the consequences and implications of their own dementia diagnosis without an increase in negative affect. The Representations and Adjustment Questionnaire (RADIX; Quinn and Clare, 2018) based on the self-regulation model (SRM; Diefenbach & Leventhal, 2003) was used as a measure of people's ability to acknowledge the implications and consequences of their dementia diagnosis. The SRM proposes that peoples' understanding and beliefs about their illness influences their responses to that illness (Diefenbach, & Leventhal, 2003). The SRM prescribes that people hold representations of their illness around five components including the identity, cause, how much control they have, the timeline of the illness and the emotional and practical consequences of the illness (Diefenbach, & Leventhal, 2003). This model has much supporting research in various illnesses (Hagger & Orbell, 2003).

As discussed earlier, the beliefs and understanding a person holds about their dementia will vary depending on their awareness and insight; which can be due to their cognitive capabilities or psychological processes such as minimising, denial or repression. The RADIX therefore provides a way to examine how the dementia is represented to them and provides a measure of their awareness and insight through measuring their beliefs and understanding about their dementia.

Given the research regarding nostalgia reducing existential threat and death anxiety, this current study also investigated if inducing nostalgia can lead to people feeling less threatened by various dementia symptoms and less anxious about death. Specifically, the following hypotheses were developed:

1) Participants in the nostalgic condition will acknowledge more consequences and implications of their dementia than those in the ordinary memory condition. Specifically, they will be able to recognise a more negative prognosis, a greater lack of control over the diagnosis and a greater amount of practical and emotional consequences.
2) Participants in the nostalgic condition will rate symptoms of dementia as less threatening than those in the ordinary memory condition.
3) Participants in the nostalgic condition will have reduced death anxiety than those in the ordinary memory condition.
4) Increased ability to recognise the impact of dementia in the nostalgic condition will not be associated with an increase in levels of negative affect.

Method

Design

The design was a between-group, randomised experimental design.

Participants

Participants with a diagnosis of Alzheimer's disease, vascular or mixed dementia were recruited (N=18) from the Research Institute for the Care of the Elderly (RICE).

Inclusion Criteria

1. A diagnosis made within the previous 18 months by a consultant psychiatrist of either probable Alzheimer's disease according to the NINCDS-ADRDA criteria (McKhann et al., 1984) or probable Vascular Dementia according to the NINDS-AIREN criteria (Román et al., 1993) or a mixed form of these;
2. Mild levels of cognitive impairment, for instance an MMSE score ≥18 (Tombaugh & McIntyre, 2002) or equivalent score on an alternative assessment tool);
3. The capacity to consent to be part of the research;
4. Sufficient communication skills to be able to take part in the research.

Exclusion criteria

1. A significant history of pre-morbid mental health problems
2. A diagnosis of dementia with Lewy Bodies (McKeith, 2002) or Frontal-temporal dementia (Snowden, Neary & Mann 2002)
3. Deficits in short-term memory are not a primary cause of disability.

Measures

Brief demographics form

This obtained information on the participant's age, gender, ethnicity, accommodation status, relationship status, time since dementia diagnosis and type of dementia.

The Geriatric Anxiety Inventory (GAI)

A 20 item self-report questionnaire designed specifically for measuring anxiety in older adults with high internal reliability; Cronbach's $\alpha = 0.91$ (Pachana, et al., 2007). This questionnaire is a valid and reliable measure in older adults including those with mild dementia (Craighton, Davison & Kissane, 2018) with a cut off of 9 having a sensitivity of 90% and a specificity of 86.3% for detecting clinical levels of anxiety.

Short form of the Geriatric Depression Scale (GDS-s)

A 15 item self-report questionnaire designed specifically for measuring depression in older adults (Yesavage, 1983). A cut of score of 5 or greater indicates depression with 10 or greater being indicative of severe depression. Internal consistency has been shown to be high (Cronbach's $\alpha = 0.94$). It has been found to be a valid measure of depression in those with mild to moderate dementia (Fehr, Larrabee & Crook, 1992).

A Nostalgia Manipulation Check

A 3-item questionnaire to assess if the nostalgia intervention successfully induced nostalgia. Each question is rated on a 6-point Likert scale ranging from strongly disagree to strongly agree. This questionnaire has been successfully completed by

people with dementia (Ismail et al., 2018). In this study, Cronbach's α was 0.93 indicating excellent internal consistency.

The Positive and Negative Affect Schedule (PANAS)

A 20-item scale comprised of two scales, measuring positive and negative affect on a five-point Likert scale, (Watson, Clark, & Tellegen, 1988.) Cronbach's alpha ranges from 0.86 to 0.90 on the positive scale and 0.84 to 0.87 on the negative scale. This questionnaire has also been successfully completed by people with dementia (Ismail et al., 2018). In this study Cronbach's α ranged from 0.87 to 0.89 on the positive affect scale and ranged from 0.72 to 0.74 on the negative affect scale indicating good internal consistency.

Representations and Adjustment Index (RADIX)

A 23-item scale that assess elements of Dementia Representations (Quinn, Morris & Clare, 2018). Representations reflect a person's understanding of dementia. They have five components. The first of these is the identity the person ascribes to the condition; this is captured in the term the person uses to describe the condition. The other elements of Dementia Representations concern beliefs about cause, timeline, possibilities for cure/control, and consequences. The RADIX has been validated for people with mild to moderate dementia and has demonstrated acceptable psychometric properties, with good acceptability, internal reliability, and test-retest reliability (Quinn et al., 2018). The practical and emotional consequences subscales of the RADIX had a Cronbach's α of 0.80 and 0.90 respectively (Quinn et al., 2018). In this study, the practical and emotional consequences subscale scored a Cronbach's α of 0.76 and 0.80 respectively indicating good internal consistency.

Threat of Dementia Scale (ToDs)

A 13-item scale that assesses the level of threat that numerous dementia symptoms pose to the self (Cheston et al., 2019. This scale has good construct validity, and acceptable test/re-test reliability with a Cronbach's α of 0.74 (Cheston et al., 2019).

Death Anxiety Scale (DAS)

A 15-item scale that assesses anxiety about death and dying (Templer, 1970) with a Likert scale and a true/false format. The Likert scale was chosen as it enabled greater sensitivity to differences among participants and greater capacity to differentiate between high and low scores. This scale has been used extensively and has good internal consistency with a Cronbach's α of 0.84 and test re-test reliability (0.83) and good construct validity (Templer, 1970). In this study, the scale had good internal consistency with a Cronbach's α of 0.78. The scores range from 15-75 with higher scores meaning higher death anxiety. The categories are: 15-35 = low death anxiety, 36-55 = moderate death anxiety and 56-75 = high death anxiety. The scale has been used with older adults though not with those with dementia (Missler, et al., 2012).

Randomisation

Participants were randomly allocated into the nostalgic condition or the control group intervention. A sequence of random numbers was generated using a Microsoft Excel package by the external supervisor which was sent to the internal supervisor who then assigned the numbers to the questionnaire packs which was then sealed in an opaque envelope. The researcher who collected the data was unaware which condition participants were assigned to until after the consent procedure when opening the study pack. The researcher was therefore blind to the condition during the consent procedure, however, after this point they were no longer blind as they administered the materials.

Procedure

Ethical approval was obtained by the NHS Health Research Authority (Ref: 18/WM/0257) and by the University of Bath Psychology Ethics Committee (Ref: 18-259).

The study was advertised at memory services across Avon and Wiltshire Partnership Trust (AWP), 2gether Trust and the RICE clinic. The study was also advertised on 'Join Dementia Research' (JDR) which is an online self-registration service enabling people with dementia to register their interest in taking part in research. Due to lack of referrals from clinicians at AWP and 2gether and unwilling and/or unsuitable people on JDR, participants were solely recruited from the RICE clinic. See Figure 1 for recruitment flowchart diagram.

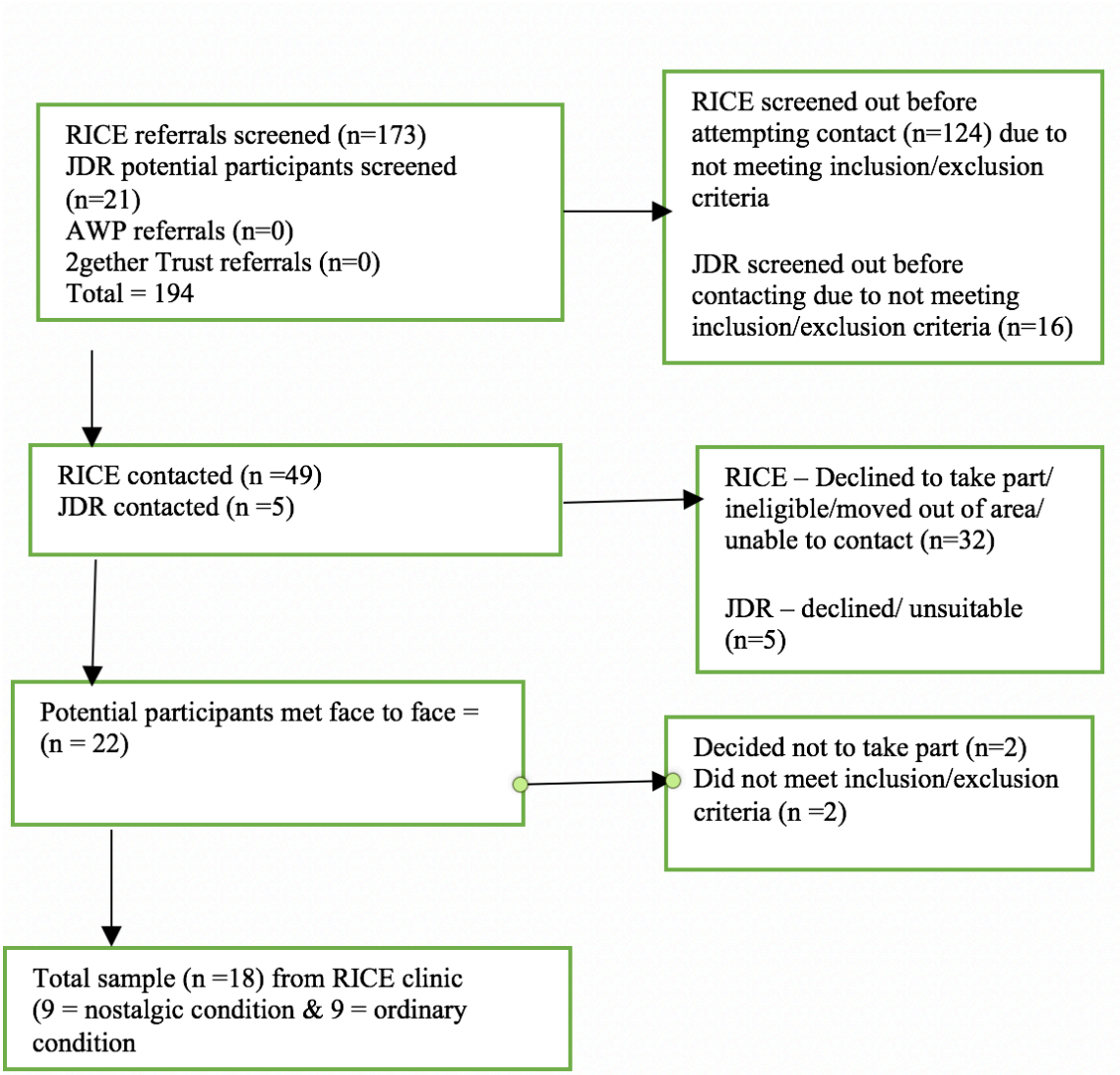

Figure 1: Recruitment flowchart

Clinicians at the RICE clinic gained consent from potential participants for the researcher to contact them. Potential participants were then contacted by the researcher and sent the Participant Information Sheet (PIS) and if they were interested a date was arranged for them to take part in the research.

A clinical assessment of potential participants' ability to give informed consent and engage in the study was undertaken through asking them to explain their understanding of the study and the topics that will be covered. Participants' most recent available cognitive screen was checked to ensure scores were within the mild range. Written informed consent was gained at the research assessment.

Once this was completed the sealed recruitment pack was opened. Participants completed a brief demographics form and the GAI and GDS as high levels of anxiety and depression may affect responses on the measures. Participants then completed the

PANAS as a measure of current positive and negative affect. Participants in the nostalgic condition were then asked to recall a nostalgic memory whereas those in the control group were asked to recall an ordinary past memory (see appendix for instructions). This is a well-established, validated method that has been used extensively in social psychology (Ismail, Cheston, Christopher & Meyrick, 2018 for a review) and has also been used in three previous studies with people with dementia (Ismail, et al. 2018).

All participants then completed a nostalgia manipulation check, the RADIX, the ToDs and the DAS. Participants then completed a repeat assessment of the PANAS in order to assess for any change in affect. The participant was reminded of the nostalgic or ordinary memory they had recalled between each questionnaire. The participant was then debriefed and informed that the study was examining the impact of nostalgic memories specifically and given the opportunity to discuss any feelings that had arisen from completing the questionnaires. See figure 2 for flowchart of study procedure.

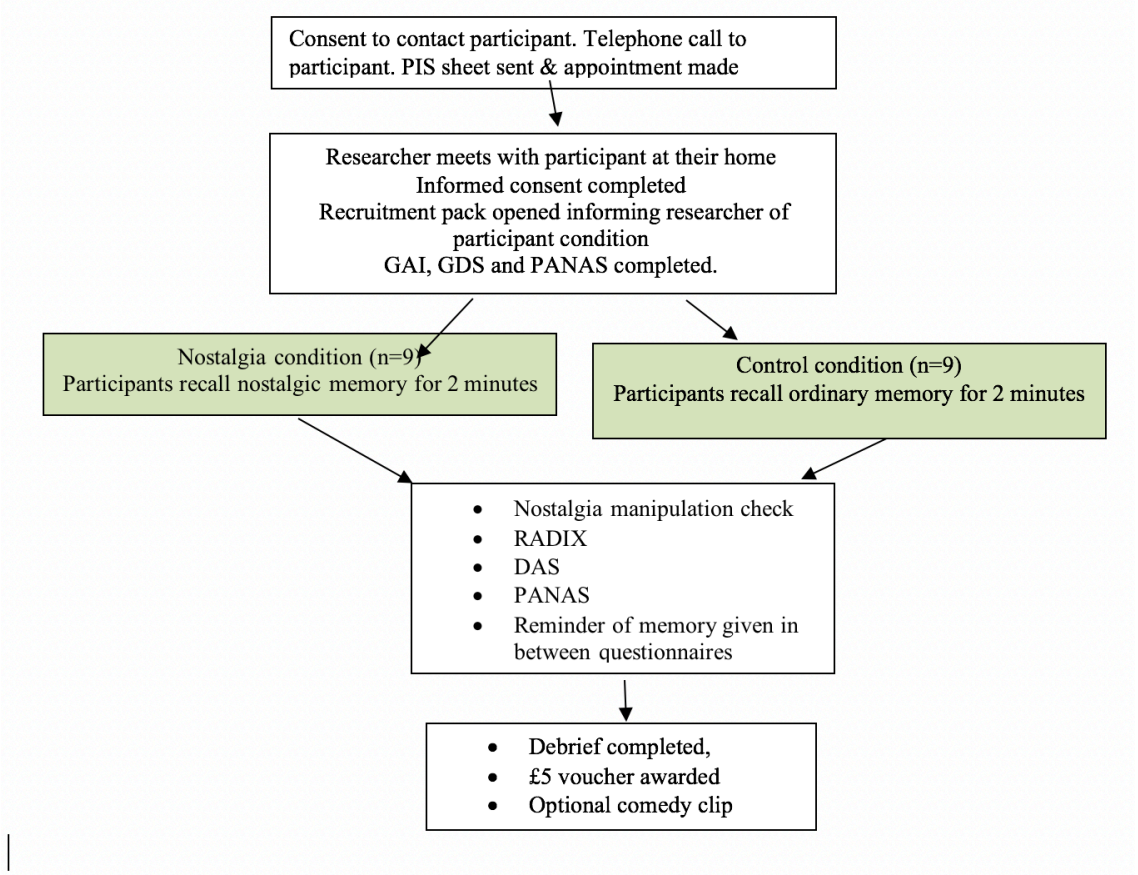

Figure 2: Flowchart of study procedure

Ethical Considerations

Given the sensitive topics included in the study, a clear protocol was developed with the appropriate action to be taken if a participant had high levels of depression or anxiety or if they experienced any distress when taking part in this research (see Dealing with Distress appendix for full details). Further safeguards that were implemented included being very explicit regarding the sensitive content of the topics when recruiting both verbally and in the PIS. The study was also piloted with a person with dementia who provided valuable feedback and helped shape the final design of the study.

Statistical Analyses

Power

According to calculations based on G Power to achieve power of 0.8 with an alpha of 0.05 and an effect size of 0.8, a sample size of 60 was deemed necessary (30 in each condition).

Missing Data

The ToDs proved difficult to administer due to participants having difficulty understanding the questionnaire and answering questions based on how they currently rated their dementia symptoms rather than hypothetically. This questionnaire was subsequently omitted from being administered after the first six participants and was not analysed. Four participants did not wish to complete the DAS due to not wishing to answer questions around the topic of death therefore 14 sets of the DAS were completed (7 in each condition).

Analysis

Analysis was performed using SPSS version 24. Due to the small sample size and the data not being distributed normally non-parametric statistics were chosen. The two conditions (nostalgia and ordinary memory) were compared using a Mann Whitney U test to test for group differences in the dependent measures (DAS & RADIX), and the PANAS. A Wilcoxon rank signed test was performed to check for any differences in each condition for positive and negative affect pre-nostalgia manipulation and post dependent measures.

Results

Table 1 depicts the categorical characteristics of the two conditions including gender, living circumstances, diagnosis, ethnicity and study location.

Table 3.1: Categorical sample characteristics of the two conditions

	Characteristics	Nostalgia Memory N (%)	Ordinary Memory N (%)
Gender	Men	3	5
	Women	6	4
Living Circumstances	Living alone	2	4
	With partner/spouse	5	5
	With other family	1	0
	In residential care	1	0
Diagnosis	Alzheimer's Disease	2	0
	Vascular Dementia	1	5
	Mixed Dementia	6	4
Ethnicity	White British	9	9
Study Location	Participants Residence	9	9

Table 2 depicts the sample characteristics of participants of the two conditions. The groups did not significantly differ in age, months since diagnosis, GDS, GAI and MMSE scores.

Table 3.2: Continuous sample characteristics of the two conditions

	Nostalgic Memory (n=9)	Ordinary Memory) (n=9)	U	Z	*P*
Age					0.340
Median	80	84	29.00	-1.021	
Range	(65-89)	(76-91)			
Months diagnosed					
Median	3	7	28.00	-1.110	0.297
Range	(1-17)	(2-15)			

GDS					
Median	3	3	27.00	-1.210	0.226
Range	(1.5-8)	(1-6)			
GAI					
Median	1	1	38.00	-0.228	-0.228
Range	(0-10)	(0-10)			
MMSE					
Median	23	24	35.50	-0.445	0.666
(Range)	(19-28)	(18-27)			

Hypothesis Testing (see Table 3)

Table 3.3:
The two conditions' scores on the nostalgia manipulation check, RADIX and DAS

	Nostalgia M (SD) (n=9)	**Control M (SD) (n=9)**	**U**	**z**	***P***	***Effect Size Cohen's D***
NMC						3.06
Median	5	2.33	0.00	-3.65	0.001	
Range	(5-6)	(1-4.67)				
RADIX Prognosis						
Median	3.00	3.00	37.00	-0.33	0.741	0.14
Range	(2-4)	(2-4)				
RADIX Control						
Median	3.00	3.00	31.5	-1.10	0.270	0.52
Range	(2-3)	(2-3)				
RADIX E.C*						
Median	2.4	2.2	38.00	-0.22	0.824	0.21
Range	(1-2.6)	(1.2-2.8)				
RADIX P.C*						
Median	2.0	2	32.5	-0.72	0.474	0.35
Range	(1-3.5)	(1.25-3)				
DAS						
(n=14)	(n=7)	(n=7)				
Median	36	40.0	14.00	-1.35	0.209	0.71
Range	(18-44)	(28-48)				

*E.C = Emotional Consequences; P.C = Practical Consequences

Nostalgic Manipulation Check

Participant's responses on the nostalgic manipulation check were totalled, averaged and analysed for differences between groups. Participants in the nostalgia condition reported feeling more nostalgic than those in the control condition, a statistically significant difference of U= 00, z = -3.654 $p < 0.001$.

Hypothesis 1 – RADIX Responses

Participants' responses to their perceived control, prognosis, emotional and practical consequences was compared between the two conditions. There were no statistically significant differences between responses to these questions.

Hypothesis 2 – ToDs Responses

This hypothesis was unable to be investigated due to participants' comprehension of the questionnaire and it subsequently being excluded.

Hypothesis 3 – DAS Responses

Participants' total score on the DAS did not differ between the nostalgia and the control arm (see Table 3). Five out of fourteen participant were categorised as having low levels of death anxiety (3 in the nostalgia condition & 2 in the ordinary condition) and nine participants were categorised as having moderate levels of death anxiety (4 in the nostalgic condition & 5 in the ordinary memory condition).

Hypothesis 4 – Change in affect

Wilcoxon signed rank tests were conducted for both positive and negative affect in the nostalgic and ordinary memory conditions to assess for any change in affect (see table 4 & 5). There was no significant difference in the nostalgic condition for positive affect (z= - 0.563, p = 0.574) or negative affect (z=.00, p = 1.00) between the two-time periods. There was also no significant difference over time in the ordinary condition for positive affect (z= -.847, p = 0.397) or negative affect (z=0, p = 1.00).

Table 3.4:
The two conditions scores on positive affect over time

	Positive Affect Time 1	Positive Affect Time 2	Z	*p*	Cohen's D Effect size
Nostalgia condition Median Range	24 (15-33)	22 (18-36)	- .563	0.574	0.09
Control condition Median Range	28 (15-40)	24 (15-39)	-0.847	0.397	0.14

Table 3.5:
The two conditions score on negative affect over time

	Negative Affect Time 1	Negative Affect Time 2	Z	*p*	Cohen's D Effect size
Nostalgia condition Median (Range)	10 (10-15)	10 (10-15)	0.00	1.00	0
Control condition Median Range	10 (10-11)	10 (10-12)	0.00	1.00	0

Discussion

This study aimed to investigate the use of nostalgia as a psychological resource in people with dementia in two ways: first by examining whether a nostalgic memory intervention enables participants to engage more with the consequences and implications of their dementia; and secondly, whether the intervention reduces death anxiety without increasing negative affect.

The results demonstrated that the experimental manipulation was successful: participants in the nostalgia intervention reported significantly higher levels of nostalgia than did those in the ordinary memory condition. However, turning to the psychological impact of that manipulation, the results are contrary to the predictions; namely, increases in nostalgia did not lead to either an increase in the participant's ability to engage with the threatening aspects of their dementia or to a reduction in death anxiety. However, a moderate effect size of 0.71 (see table 3) was detected for the DAS indicating that with a higher sample size this potentially meaningful reduction in death anxiety could have reached significance. There were no changes in affect before the nostalgia manipulation and after completion of the questionnaires in both groups.

Ability to engage with the threatening aspects of dementia

Previously, nostalgia has been shown to attenuate the MNE for recall of self-referent, dementia-related information and lead to an increased recall of self-referent information about dementia (Ismail, et al., 2018). In contrast, this study showed that nostalgia did not increase participants' ability to recognise implications about their dementia. This could suggest that awareness of the implications and consequences of one's own dementia (as measured by the RADIX) and the recall of negative self-referent information are two separate processes. Importantly, the MNE is present for the recall of highly negative self-referent information, but not for the recognition of this in both non-clinical populations (e.g. Sedikides & Green, 2009; Sedikides, Green, Saunders, Skowronski, & Zengel, 2016) and people living with dementia (Cheston et al., 2018). Given that the RADIX is a questionnaire with written statements it could be more analogous to the recognition of dementia-related statements and might therefore tap into a different process in comparison to being asked to spontaneously recall the implications and consequences of one's dementia. Given the MNE effect implies a

protective retrieval deficit, this may have manifested if participants had been asked more open, general questions regarding the impact of dementia as opposed to acknowledging specific statements.

It is important to be tentative when interpreting the non-significant finding given the small sample size resulting in the study being under powered which could have resulted in a false negative result. This is important given the influence of demographic differences and individual variation on participants' responses. For instance, there is likely to be large variability within people's experience of the emotional and practical consequences of having dementia on their life. Further, people's personality and coping styles will influence their ability to engage with their dementia. For instance, people who view illness as a sign of weakness and have high expectations may have greater desire to repress difficulties with their dementia (Weinstein, Friedland & Wagner, 1994). A randomised design aims for this variability to be similar between groups, however, this would likely require a large sample size given the varying coping strategies and impact of dementia on people's lives.

Death anxiety

Research demonstrates that older adults generally experience low levels of death anxiety compared with younger adults (Russac, Gatliff, Reece & Spottswood, 2007). However, certain factors predict higher levels of death anxiety in older adults including greater psychological difficulties, higher levels of physical problems and lower levels of ego integrity (Fortner & Neimeyer, 1999).

This study found the majority of participants that completed the DAS experienced moderate levels of death anxiety with the remainder categorised in the low death anxiety range. A TMT perspective suggests that meaning is acquired through self-esteem, cultural worldviews and relationships which enables people to reduce their existential threat (Maxfield, John, & Pyszczynski, 2014). Living with dementia can impact negatively on sense of self, relationships and identity, thus this existential buffer is vulnerable which may result in elevated death anxiety for people with dementia. Given that death anxiety has been postulated to underlie a range of mental health disorders (Iverach, Menzies & Menzies, 2006 for a review) elevated death anxiety could increase the risk of later psychological difficulties in people with dementia.

Based on TMT, this then lends itself to consider the importance of ways to attenuate the existential threat of dementia through engaging in mechanisms such as

nostalgia that bolster cultural worldviews and boost psychological resources. Though nostalgia was not shown to significantly reduce death anxiety in this study, the moderate effect size detected suggests that further investigation into nostalgic recall to bolster psychological resources to attenuate death anxiety warrants further investigation in future with a larger sample size.

Positive and negative affect

The results demonstrated that there were no significant changes in participants' positive or negative affect throughout the study regardless of condition. This provides preliminary evidence that discussing sensitive topics that are often avoided in healthcare settings is feasible and does not cause distress to people with dementia. Systemic and cultural barriers to discussing dementia and death with people can have negative implications if relevant information is not disclosed, disempowering people to make decisions about their care and preventing them adjusting to and accepting their diagnosis.

This was demonstrated through the difficulties with recruitment in this study. Some memory services and carers voiced reluctance at discussing the study with potential participants. This is in line with other research with vulnerable groups where gatekeeping can be a barrier in recruiting (Snowden & Young, 2017), often due to the gatekeeper's own anxieties, concerns, lack of motivation and understanding about the research (McFadyen & Rankin, 2016).

Limitations

Unlike the three previous nostalgia studies involving people with dementia (Ismail et al, 2018) this study did not include a state functions of nostalgia scale (SSNFS) which measures psychological resources including social connectedness, continuity and meaning in life. This was removed after piloting the study with a person with dementia who commented on finding the number of questionnaires burdensome. Given that the three previous nostalgia studies found that nostalgia resulted in a significant boost in psychological resources it was assumed that the nostalgia manipulation would also do so in this study. However, without explicitly measuring this, it cannot be said for certain that participants in the study were experiencing a significantly greater psychological boost compared to those in the ordinary memory condition.

Another possible limitation is that the RADIX may have not accurately captured people's ability to engage with their dementia. As discussed previously it may be more analogous to recognition rather than recall. Additionally, it was originally designed to capture peoples' beliefs, representations and adjustment to dementia. Given the complexity of the concept of insight and awareness there has been difficulty finding a reliable and valid way to measure these constructs with adequate psychometric properties (e.g. Graham, Kunik, Doody & Snow, 2005; Markova & Berrios, 2001). A recent semi-structured interview by Parrao et al., (2017) has attempted to overcome the methodological limitations of previous measures, however, this interview is lengthy and requires an informant perspective.

Previous research on psychological aspects impacting awareness on dementia have also focused on qualitative studies (Cheston, 2013; Clare, 2003). For example, Clare's (2003) study consisting of qualitative interviews of people with early stage Alzheimer's Disease demonstrated psychological strategies that people adopt in response to their diagnosis ranging from self-maintaining to self-adjusting strategies. Future research could consider developing a measure that examines dementia awareness more specifically through possibly quantifying the psychological strategies and themes that have arisen from the qualitative research.

The small sample size and lack of diversity within the sample are major limitations preventing strong conclusions. A more diverse sample with different cultural and ethnic backgrounds could have provided different responses to considering implications of dementia and beliefs around death. Significantly, the current sample was self-selecting as potential participants declined to take part in the study due to not being willing to discuss their dementia or the topic of death. Further, within the sample, four participants declined the death anxiety component. Future research is needed to examine these individual differences in people's ways of approaching and avoiding their dementia and the implications of these coping styles.

Conclusions, clinical implications and future research

In conclusion, nostalgia did not impact on recognising the consequences of one's dementia and levels of death anxiety. However, discussing sensitive topics is feasible in this population though it is important to ensure people are initially willing to engage in these topics given that many people declined to take part. Clinical implications include awareness that death anxiety may be raised in people with

dementia and consideration of ways to attenuate this is important, which may include post-diagnostic therapeutic support to help people adjust to their diagnosis.

Future research could examine different ways to capture people's ability to engage in the threatening aspects of one's dementia diagnosis. Future research would also benefit from examining individual responses to illness and coping in dementia and the impact of these coping strategies on well-being. Further, given the difficulties with recruitment, future research examining staff and carer's perspectives on discussing dementia and death could help reduce avoidance with this important topic.

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Executive Summary

Receiving a dementia diagnosis can cause worry, uncertainty and fear. Research has shown that sometimes people can find it difficult to have an understanding and awareness of their dementia diagnosis. This may be because of the memory difficulties that are part of the illness, or it may be because dementia is frightening, and people prefer not to think about it. Whatever the causes, there are a number of knock-on effects to this lack of awareness. These can include psychological problems and a decreased ability to function effectively on a day-by-day basis. It can also have a negative effect on the people around them. Some people affected by dementia can often understandably feel threatened and this study was interested in looking at ways that can have reduce this threat and worries.

This study looked at whether we could help people recognise the consequences of their dementia and reduce how anxious they may feel about death by increasing psychological resources such as self-esteem, meaning in life and feeling socially connected to others. Previous research has shown that one potential way we can increase these resources is by asking people to recall a nostalgic memory. This seems to be because nostalgia increases self-esteem, social connectedness and meaning in life in a way that other memories do not. Previous research has also shown that when people with dementia recall a nostalgic memory it enables them to remember more self-threatening statements about dementia without making them feel more negative. This study set out to continue this research and see if discussing a nostalgic memory enabled people to recognise the implications of their dementia and reduce their worries about death without making them feel more negative.

This study involved recruiting people with mild dementia who had recently been diagnosed. Then this study involved randomly assigning people to either think about an ordinary memory or a nostalgic memory. This meant that everyone who took part had an equal chance of either being asked to remember an ordinary memory or a nostalgic memory. Recruiting people to take part in this study was difficult and 18 people in total completed the study; 9 were asked to discuss a nostalgic memory and 9 were asked to discuss an ordinary memory. Everyone then answered questionnaires about people's understanding and awareness of their dementia and how anxious they felt about death. We did this because we were testing to see if those who remembered a nostalgic

memory were able to recognise the consequences of their dementia and feel less anxious about death compared to those who remembered an ordinary memory.

What we found was people who discussed a nostalgic memory felt significantly more nostalgic than those who discussed an ordinary memory. However, we did not find any differences in how much people recognised their consequences of their dementia or how anxious they felt about death. People's mood did not significantly change throughout taking part in the study which suggests that people with mild dementia can discuss these sensitive topics. We also found that the majority of people who took part in this study had moderate levels of death anxiety which may be higher than older adults without dementia.

Due to the small sample size in this study, it is difficult to make any strong conclusions as it may be that no difference was found because the sample was too small to find an effect. However, it may also be because thinking about nostalgia does not make a difference in how aware people are about their dementia or how anxious they are about death. Clinicians should be aware that anxiety about death may be raised in people with dementia and should consider ways to help reduce this, for example, post-diagnostic therapeutic support to help people adjust to their diagnosis.

As people who did take part did not find it difficult to talk about these topics, this suggests that talking about difficult topics such as consequences of dementia and death that can often be avoided by carers and staff is feasible. This is important as if these topics are avoided it can disempower people by preventing them from making decisions about their care and adjusting and accepting their dementia diagnosis. However, it is also important to note that some people did not want to take part in the study because of the topics it covered. Further, four people in the sample did not want to answer the questionnaire on anxieties about death. This suggests that it is very important to ask people thoroughly if they are willing to discuss sensitive topics and that it remains a collaborative, thoughtful process throughout.

Future research could examine different ways to capture people's ability to recognise the implications of their dementia diagnosis. Future research would also benefit from examining individual responses to illness and coping in dementia and the impact of these coping strategies on people's well-being. Further, given the difficulties with recruitment, future research examining staff and carer's perspectives on discussing dementia and death could help reduce avoidance with this important topic.

Connecting Narrative

The aim of this section is to share my reflections on my learning from my research projects and case studies.

Service Improvement Project

I was lucky enough as an assistant psychologist to attend a training day with Dr Mary Welford on Compassion Focused Therapy (CFT). This fostered my interest in this therapeutic approach and I was keen for opportunities to increase my understanding and knowledge of this model. When Dr Anna Strudwick, presented the opportunity to evaluate and improve an age inclusive CFT group in her service, I jumped at the chance. A Compassionate Mind's group based on CFT had been running for both working age and older adults with positive feedback for a few cohorts. The service felt it would be beneficial to examine the quantitative data to assess the efficiency of the project and also to gain more in-depth qualitative feedback on the experience of a mixed age range.

Interviewing participants who had attended the CM group was an enjoyable experience. I was struck by hearing about the significant positive impact the group had on the participants and what they had learnt. I was very grateful for participants giving up their time to discuss the personal impact of the group and for being so honest, thoughtful and reflective with their responses. It made me consider how it is impossible to capture on a quantitative measure the holistic impact that a therapy group can have and the significance of utilising qualitative data to supplement quantitative methods whenever possible. This especially seems pertinent when assessing the efficiency of new groups as there is so much emphasis on changes on certain scores and 'symptoms' without recognition of all the knowledge, skills and perspectives a person may have gathered that could have had a significant positive impact on well-being.

Transcribing the interviews was lengthy but a helpful way to familiarise myself with the data. However, when it came to the analysis part I felt uneasy at where to start having not had any experience at all in qualitative methods. This was with the exception that one of our assignments in the first term consisted of critiquing a qualitative paper. This assignment proved helpful in considering all the important elements to consider and was a useful introduction into this unknown, nebulous area. I recalled spending a significant amount of time reading the various epistemological stances that could be taken and the importance of being aware of the position you are taking when analysing

the data. The more reading I did, the more nervous I became to start analysing the data due to fear over not analysing it correctly! In the end my supervisor, Dr Anna Strudwick, gave me some good advice reminding me that the analysis is an ongoing process rather than a linear process which encouraged me to just get started. When I started this became an enjoyable process though I under estimated the vast amount of time it takes to code the entire data set and continually read it and group themes. I think the knowledge that there is no definite 'correct' result to arrive at and themes can be continually re-defined and combined meant that it was difficult to know when to stop analysing. However, I now have a better understanding that the aim of qualitative research is to explicitly recognise your own interpretation of the data rather than the focus on another person being able to replicate it exactly.

The interviews gave rich information about people's experiences of the CM group and in particular the experience of an age inclusive range. The detailed information that people gave resulted in some tangible recommendations to improve the group. This project felt particularly useful in that some brilliant concrete changes were made to the CM group as a direct result of the recommendations from the project. It was great that the project provided a platform that enabled participants to have their voices heard which will improve the service for future people. I am proud of this project and demonstrated to me the power of research in enabling direct improvements to a service.

Main Research Project

Part of my pre-training experience had been working in older adult services including working with people experiencing dementia. Working as part of a memory service and co-facilitating therapeutic groups that included people with dementia made me recognise the huge psychological impact that this disease has on the individual and family. I was really interested therefore when I read about Professor Richard Cheston's research interests at our research fair which included conceptualising dementia as an existential threat. His research included drawing on the wider social psychology literature that consider how non-clinical populations manage existential threats and applying this to people with dementia. I found this fascinating and contacted Professor Richard Cheston to discuss ideas to take these recent findings forward in order to conduct my main research project.

Ethical Approval

Completing ethical approval was a much bigger hurdle than anticipated; the process was arduous and incredibly time-consuming. It continued for many more months than I had accounted for and took a considerable amount of co-ordination. I was very grateful for the advice from previous trainees who had taken the time to complete guides for of all the steps involved. However, the benefits of completing such a detailed process meant that it allowed for a thorough consideration of all the elements and issues encompassing the project. It was also good to understand the process if I choose to recruit from the NHS in any future research.

Recruitment

The original plan for recruitment was to widely cast my net and I contacted clinicians in the memory services of various NHS trusts across the South West region. Ambitiously, I also included older adult services from the NHS trust I previously worked in Wales as an additional recruitment site. The primary site for recruitment was the Research Institute for the Care of the Elderly (RICE) clinic in Bath as it was already set up excellently for research. Once my ethical approval had finally been completed, I started the recruitment process.

This involved initially focusing on the RICE clinic and I collaborated with the clinical trials co-ordinator about how to maximise recruitment. The initial plan was for the co-ordinator and other clinicians to introduce my study to participants who met the inclusion and exclusion criteria and were willing to be contacted and then complete and send a referral form with the potential participants details to me. Unfortunately, due to clinicians and the trial co-ordinator being very busy this yielded only a couple of referrals over the first three months. This was quite a stressful period as I had optimistically assumed there would have been plenty of referrals.

I also sent out information about my research study to be placed in various carer groups and advertised my study on the research page of various trusts. I then focused on attending team meetings of local memory services to explain my research and the recruitment process. It was interesting to note the various responses when explaining my research project; some clinicians voiced that they would feel uncomfortable at asking people with a dementia diagnosis to take part in a research project that focused on discussing the impact of dementia and death anxiety. I emphasised that any potential participant would have a thorough explanation of the study and the sensitive topics that it includes in order to make an informed decision about whether they would like to take

part. However, some staff still felt they would not even like to broach the subject with people. Despite numerous attempts at promoting recruitment in local memory services, this did not yield any referrals.

Another issue which likely impacted recruitment is that the memory services that people attended were at the assessment stage of being diagnosed with dementia and there was usually not any post diagnostic follow-up. Understandably, asking people who had immediately been diagnosed would not have been appropriate timing. As many of the services did not tend to see people after they were diagnosed, this limited the chance to advertise the study.

On reflection, I now have a better understanding of the barriers that would impact on recruitment and how I would do things differently. Asking clinicians to introduce the study to participants and then complete a referral form asking them details for the person's dementia, the dates and scores of recent cognitive screens was a big task. Without having established links in the majority of the memory services this meant that it was difficult for clinicians to remember and be motivated to advertise this. On reflection, thoroughly establishing these links in the very early stages of the project and having periodic reminders or visits to the services to refresh clinicians' memory and encourage recruitment may have been beneficial.

Resistance to the idea from staff and carer's likely had an impact on recruitment. This was unsurprising when the study area was considering ways to help people engage with dementia as the threat of it impacts on those around the person as well as the person with dementia. I spoke to numerous carers who felt they would not like to even mention the study to the people they care for as they felt it was not an appropriate topic. This made me consider gatekeeping of vulnerable populations in research and how if people are able to give informed consent the importance of giving people the choice to choose. I think discussing this more openly with staff teams may have helped address people's thoughts and feelings around this issue which could have enabled clinicians to think differently about the importance of not assuming people would not like to take part.

After the problems encountered with local services, I focused on the RICE clinic for the reminder of the time. I met with the clinical trials co-ordinator on a very regular basis which resulted in an increase in referrals.

Meeting Participants

In my excitement of researching such an interesting area I hadn't fully comprehended the feasibility of the project. Visiting people face-to-face was very time intensive and involved a lot of travelling. Further, ringing potential participants, carers and residential homes to arrange appointments and the administration of posting letters and participant information sheets was time consuming. This made me reflect on the importance of a thorough consideration of the pragmatics when considering a research project.

Similarly, I got caught up in the theoretical interest of the area without thinking of the emotional impact on myself of repeatedly asking people sensitive questions around death anxiety which are often culturally neglected and avoided from discussions. This was interesting as due to the sample being self-selecting; i.e. had already clearly expressed they were happy to discuss dementia and death prior to taking part, the vast majority of participants did not have any reservations about answering these questions. On reflection, the timing of visiting the majority of participants alongside a placement where I had a caseload of people experiencing neurological life-limiting conditions perhaps made this more difficult. It was helpful having a regular check in with my internal supervisor, Dr Anna Strudwick, to discuss and reflect on these feelings.

There were very valuable aspects to meeting face-to-face with participants. I am incredibly grateful to all the participants that I met who gave up their time and answered sensitive questions that are very rarely discussed. I learnt a lot from each single participant. It was also interesting to note how qualitatively different it felt when discussing nostalgic memories versus an ordinary memory and I had not expected this difference to be so powerful.

Literature Review

My initial literature review idea was considering the effectiveness of ACT in treating PTSD. I had learnt quite a bit about ACT pre-training and had read some articles of its increasing use in trauma work. Given that CBT-T is the gold standard treatment for PTSD, it felt important to research this area to assess ACT's effectiveness and how it compares. Unfortunately, at my PAS (project approval session) the panel did not agree, and the project was not approved. I then considered that it may be interesting and helpful to link my literature review with my main research project and considered a qualitative review around the impact of psychotherapy groups in people with dementia.

However, I was informed that this did not show sufficient breadth in my projects, so it was back to the drawing board! There was lots of other research areas that interested me, so I spent lots of time searching for various ideas, however, it felt really difficult to identify a suitable gap in the literature and find something that had not already been recently reviewed! I realised that this may be because I was not familiar enough with any specific research area at this stage.

I then spoke with a member of the course team, Dr Catherine Butler, who specialist interests were transgender and sexual health. I had a little experience in sexual health from my first-year placement and had found this an interesting area. Catherine highlighted that there was there was so much emphasis on the physical aspects of sexual functioning in transgender with little consideration of the psychological factors that could be influencing. I thought this was a really interesting area and idea for a literature review and would give me an opportunity to find about more about an area that I had very little knowledge about.

Due to the limited area in the field it felt important to do a wide scope as possible to find as many articles related, however, this meant many thousands of search hits! On completion of my search results, a similar review was published examining sexuality and sexual experiences during gender transition. This was a stressful period, however on closer examination we recognised that the reviews were quite different, though there was an overlap with some studies my review had a different focus. My review focused on both quantitative papers in addition to qualitative research and had a focus on examining psychological factors and how these related to psychological theory on sexual dysfunction.

I had never written a literature review before and it felt like a nebulous task. Having varying groups and varying methodology made it difficult to collate and consider. However, it was helpful to talk through my findings with my supervisor to recognise the themes that were apparent across the literature. There were some very interesting findings and is an area of research that requires more focus on and I hope my review will be of use to clinicians working in sexual health and transgender to helping consider the contextual factors.

Case studies

Though this wasn't a consistent feeling, overall, I really enjoyed writing up my case studies and found them very valuable exercises. I completed four CBT case studies

with the final one being a neuropsychological assessment. The case studies covered a range of presentations in different settings; which will be a helpful resource for when working with similar issues in the future. It has been interested development in how the case studies initially felt like a huge task with so many different areas to consider and co-ordinate where in contrast the last few come together quite naturally.

My first case study I decided to do a single case experimental design. I was very keen to ensure I gave the measures weekly with an appropriate baseline followed by the intervention period that I rushed into the decision of what measures to use. However, by being so keen to administer the measure meant that I probably did not choose the most useful measure. This introduced me to the importance of choosing the most appropriate measure, however, this can be difficult if making the decision before a thorough assessment and formulation.

The case studies were helpful in providing the opportunity for a deeper exploration of the theoretical background of the presenting issue to ensure that theory-practice links were being made. It was also a helpful opportunity to review the most recent literature in that area which was clinically helpful. The case studies provided extra time to consider the problem on a deeper level which felt really useful for promoting reflection. Case studies also helped me consider the importance of re-formulating regularly. Whilst some of the cases followed a relatively straightforward trajectory where the intervention worked well derived from the formulation, other times it did not. It was helpful to think of alternative ways to formulate a case which could lead to new perspectives.

Summary

The research projects have been the most challenging aspect of the course for me. I struggled with juggling the number of projects and case studies and at times this was a very stressful experience. However, during these times I was lucky to receive excellent support and guidance from my research supervisors. The range of projects have developed my research skills and I am more aware of the realities and difficulties of conducting research whilst working clinically. I feel I have learnt a lot and going forward I feel I would be in a stronger position to consider what I would do differently in the future. It is incredibly rewarding when realising the value that research can have in improving clients experience in a service and I would like to continue conducting more research at some point in the future (however perhaps one project at a time!)

Appendix 1.1: Table of Included Papers

Authors	Aims	Sample	Data Collection Method	Key Findings
Bauer, Redman, Bradley & Scheim (2013)	To describe the experiences of transmen in relation to sexual satisfaction, sexual orientation, sexual identity, sexual risk and psychosocial factors.	227 transmen 173 of this sample were trans GB-MSM (sexual minority identity therefore not exclusively attracted to cis-gender women). Participants all identified as trans and were not required to have started or completed a medical or/and social transition. Trans men (n=227) Trans GB-MSM (n=173)	Quantitative method: self-reported questionnaires online covering topics including: sexual behaviours, sexual orientation identity, transphobic violence, sexual satisfaction (subscale of multi-dimensional sexual self-concept); Sexual body image worries scale (created by authors of study); Centre for Epidemiological Studies Depression Scale.	227 transmen only 1/3 identifying as straight. Remainder of results focused on 173 trans GB-MSM: Wide range of sexual behaviours reported. 57.4% reported moderate-high sexual body image worries. High levels of moderate-severe depression reported (>73%) 27.5% low, 33.3% moderate & 39.2% high levels of sexual satisfaction. Experience of transphobic violence: 47% none, 36.1% verbal harassment & 16.9% physical or sexual assault. 45% monogamous relationship.
Bockting, Benner & Coleman (2009)	To provide insight into the psychosexual adjustment and psychosocial challenges of transmen and how they create their sexuality and identity.	25 Transmen who had received both hormone therapy & completed masculinising chest surgery. (n=25) Comparison group of gay & bisexual non-trans men included.	Qualitative methods: semi-structured interviews. Quantitative methods: Klein Sexual Orientation Grid; 2 subscales of Derogatis sexual functioning inventory; Rosenburg self-esteem scale, Minnesota Multiphasic Personality Inventory. Additional questions asked on gender identity, social sex role & transvestic fetish.	Trans participants appear to develop their own transgender sexuality which is distinct from female & male sexuality.
Brown (2010)	Examined sexual minority women experiences of sexual and romantic relationships with trans men.	20 participants who currently or had been previously partnered with a trans man and identified as non-heterosexual	Semi-structured interviews	Impact of transitioning on sexuality resulted in a process of renegotiating bodies and sexual connection. Negative impacts on sexual experiences more likely if partner had a past history of trauma and by if they identified as a lesbian. Positive findings included a more embodied partner who had an increased sexual drive.
Doorduin & Van Berlo (2014)	To explore trans people's experiences of sexuality	12 trans people; 6 trans men (2 no medical intervention, 2 had received hormones & chest surgery, 2 completed top & bottom surgery); 6 trans women (2 no medical intervention, 1 hormone therapy & 3 hormone therapy & vaginoplasty). (n=12)	Qualitative Methods: Semi-structured interviews	Three themes that impacted sexuality; incongruence between gender identity & gendered embodiment and/or social gender perception; physical changes in sexual functioning after treatment & sexual development. Additional themes

				included cross-gender fantasising & sexual identity development.
Joslin-Roher & Wheeler (2008)	To explore the transition experience of partners of transgender men	9 partners of transgender individuals	Qualitative methods: Semi-structured interviews	Mixed findings of impact of transition on sexual experiences: Trans person increased confidence and satisfaction with their bodies positively impacted on the sexual relationship. Challenges included changes in the sexual relationship, including change in sex roles, different sexual acts being preferred, communication problems around sex, change in sex drive due to testosterone & trans person unhappiness with body. Impact of recovering from surgery resulting in difficulty in engaging in sex.
Lindroth (2017)	To explore sexual health among trans people in Sweden	796 respondents to survey; stage of transition unknown. 20 participants in qualitative interviews. Range of social and medical transitioning stage; from not received SRS to fully legally and medically transitioned.	Quantitative methods: survey. Qualitative method: Semi-structured interviews.	Importance of acceptance of the body if not having SRS. Some experience anxiety, fear, uncertainty & disrespect in sexual experiences, which can lead to avoidance of sex. High levels of sexual assault. Some been treated as fetish or sex object. Some reported offensive treatment within transgender care due to heteronormative assumptions. Others report happiness and freedom related to sexual experiences. 23% satisfied with sex life.
Mendelson (2015)	To explore sexual satisfaction in trans women	9 transwomen who varied at what stage they had transitioned, 1 no medical transition, 7 Hormone therapy and 1 vaginal surgery.	Qualitative Methods: Semi-structured interviews.	Four main themes included; Transitioning had impacted on sexuality through a change in experiences, sexual preferences and practices; A shift in experience of orgasm and sexual satisfaction. A shift in gender role adherence or stereotypes. The impact of physical side effects.
Nikkelen, & Kreukels, (2018)	Exploring sexual experiences of trans people considering the desire for gender-confirming interventions, psychological well-being & body satisfaction	325 transwomen & 251 transmen. The participants were divided up into those with no GCT desire, those who desired further GCT & those who have finished GCT.	Quantitative Method: Survey	Body satisfaction has a significant role in impacting positively on sexual feelings. Body satisfaction was positively related to all indicators of sexual behaviour and feelings.

				GCT impacts positively on sexual feelings in transwomen, however, this was not as evident in transmen.
Pfeiffer (2008)	Exploring body image in sexuality	5 lesbian partners of transmen	Qualitative methods: Semi-structured interviews	Partners body dysphoria considerably impacts willingness and ability to share body both sexually and non-sexually, may make partner question her own body image and relationship with her body. Absence of a sexual relationship as a result of poor body image contributes to low self-confidence
Platt & Bollard (2016)	To explore the nature of transgender people's relationships.	38 trans adults	Qualitative methods: Semi-structured interviews	Physical and emotional sexual challenges. Interpersonal sexual challenges included partners reactions in sexual situations and difficulty in finding a partner who will accept them for who they are, including their bodies. Intrapersonal difficulties included body dysphoria and avoidance of certain body parts leading to difficulties and insecurities impacting on sexual relationships.
Riggs, von Doussa & Power (2015)	Exploring the family and romantic relationships of trans and gender diverse Australians	160 trans individuals	Quantitative and qualitative methods:	Anxiety over potential responses Discrimination from potential partners Lack of own self-acceptance Being treated as a fetish object Wanting romantic not sexual relationship Negative responses to genitalia
Riggs, von Doussa & Power (2017)	To explore how trans people negotiate sexual relationships	13 trans individuals	Qualitative: semi-structured interviews	themes included; Negative effects of cis-genderism; Effects of gender dysphoria upon intimacy; Effects of medical aspects on transitioning; Pragmatic decisions about non-intimacy and intimacy between transgender partners
Rosenburg, Tilley & Morgan (2019)	To explore Australians women's experience of sexuality, intimacy & gender affirming hormone therapy	12 trans females	Qualitative: Semi-structured interviews	-Positive/affirming experiences of sexuality -Psychological and physio-sexual shifts -Physiological and appearance changes -Psychophysical shifts in orgasmic experiences
Sammons (2010)	To explore the impact of body image on sexual pleasure.	33 trans women who had undergone SRS at least 6 months prior to study.	Quantitative measures Measures - Sammons Body Image & Sexual Pleasure Questionnaire	Sexual pleasure scores after surgery being significantly higher than before surgery

				Body image scores significantly higher after SRS
Schiem and Bauer (2017)	To identify psychosocial and demographic factors associated with sexual inactivity in transwomen	173 transwomen who had ever been sexually active.	Quantitative Measures included: Multidimensional Sexual Self-concept questionnaire measure of trans-related sexual worries (created by authors of study); Centre for Epidemiological Studies Depression Scale.	Sexual inactivity independently associated with being older and childhood sexual abuse. Transphobic harassment, higher levels of trans sexual body image worries & reduced sexual satisfaction associated with sexual inactivity.
Schilt and Windsor (2014)	Explore how transmen decisions about their body modifications impact on their sexuality, sexual experiences and sense of gender.	74 transmen 96% on testosterone, 68% chest surgery, 25% hysterectomies, 7% genital surgeries.	Qualitative: semi-structured interviews	Findings and themes included; Theme of gendered embodiment – feeling comfortable in achieving gender and body aligning, however, often not through completing genital surgery thus challenging cissexual assumptions. Sexual habitus – renegotiation of sexual preferences, practices and identities.
Tree-McGrath, Puckett, Reisner, Pantalone (2018)	To explore the positive and negative aspects of sexuality and sexual behaviour in transmen who have sex with men (MSM).	16 transmen MSM	Qualitative: Semi-structured interviews.	Four main themes: Harmful social influences; support and validation of a trans masculine identity; self-exploration and self-acceptance; internalised oppression. Living in a heteronormative society has important implications for transmen sexuality.
Weyers (2008)	To determine sexual well-being, satisfaction with body, physical and emotional well-being in transwomen who have completed SRS.	50 Trans women who had undergone SRS at least 6 months earlier.	Quantitative methods; Short-Form-36 Health Survery; Female Sexual Function Index.	Transwomen scored significantly lower on the FSFS than a reference group of cis-women. Transwomen in heterosexual relationship were at comparable levels with the reference group. Sexual satisfaction was highly dependent on relationship status and linked to sexual orientation; more satisfaction in heterosexual than homosexual relationship though causal associations were not established. Correlation with total FSFS score and satisfaction how others perceived their female appearance.
Williams, Weinberg & Rosenberger (2013)	To explore how trans men experience their gender identity and how this is embodied in their sexuality	25 trans men	Qualitative method: semi-structured interviews	Trans men varied in how much their gender and sexuality were connected to each other. Trans men have a range of sexual identities.. Large amount of individual variation in what defines their bodies as a masculine and what sexual acts and body parts are considered preferable in sex.

Appendix 1.2: CASP checklist for qualitative studies

Author	Clear Aims	Appropriate Method	Appropriate research design	Appropriate recruitment strategy	Appropriate data collection	Research relationships considered	Ethical Issues considered	Rigorous Analysis	Clear Findings	Value of research
Bockting, et al. (2009)	✓	✓	✓	✓	X	X	✓	Unclear	✓	✓
Brown (2010)	✓	✓	✓	✓	✓	X	Unclear	✓	✓	✓
Doorduin & Van Berlo (2014)	✓	✓	✓	✓	✓	Unclear	Unclear	✓	✓	X
Joslin-Roher & Wheeler (2008)	✓	✓	✓	✓	✓	Unclear	Unclear	✓	✓	✓
Mendelson (2015)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Pfeffer, (2008)	✓	✓	✓	✓	Unclear	✓	Unclear	Unclear	Unclear	✓
Platt & Bollard (2016)	✓	✓	✓	✓	✓	✓	Unclear	✓	✓	✓
Riggs et al. (2015)	✓	✓	✓	✓	✓	Unclear	✓	✓	✓	✓
Rosenburg et al. (2019)	✓	✓	✓	✓	Unclear	✓	✓	✓	Unclear	Unclear
Schilt & Windsor (2014)	✓	✓	✓	✓	✓	X	X	✓	✓	X
Tree-McGrath, et al. (2018)	✓	✓	✓	✓	Unclear	✓	Unclear	✓	✓	✓
Williams et al. (2013)	✓	✓	✓	✓	✓	X	✓	Unclear	✓	Unclear

Appendix 1.3 – CASP checklist for quantitative studies

Author	Clear Focused Issue	Appropriate recruitment	Exposure accurately measured	Outcome accurately measured	Identified/taken account of confounding variables	Follow-up of participants long/complete enough	Results clear	Results precise	Believability of results	Study fit with other evidence	Implications of results clear
Bauer et al (2013)	✓	✓	N/A	Unclear	✓	N/A	✓	✓	✓	✓	✓
Lindroth (2017)	✓	✓	N/A	✓	✓	N/A	✓	✓	✓	✓	✓
Nikkelen, e & Kreukels (2018)	✓	✓	N/A	✓	✓	N/A	✓	✓	✓	✓	✓
Riggs, von Doussa & Power (2017)	✓	✓	N/A	Unclear	✓	N/A	✓	✓	✓	✓	✓
Sammons (2010)	✓	✓	N/A	Unclear	X	N/A	✓	Unclear	✓	✓	✓
Schiem & Bauer (2017)	✓	✓	N/A	unclear	✓	N/A	✓	✓	✓	✓	✓
Weyers et al	✓	✓	N/A	✓	✓	N/A	✓	✓	✓	✓	✓

Appendix 1.4 – The international Journal of Transgenderism

Authors' Guidelines

I GENERAL AUTHORS' GUIDELINES

The *International Journal of Transgenderism* welcomes the submission of original scholarly articles on any aspect of transgenderism from within any discipline. Articles submitted are subject to the usual academic processes of anonymous peer review.

The journal also occasionally re-publishes previously published articles and books, which are of significant interest, and which may not be readily available; suggestions, which the editors may consider for future issues, are welcome.

SUBMISSION

- Contributions should not already have been published nor should they be currently under consideration elsewhere.
- Articles should be submitted to either of the associate editors electronically, either on disk or by e-mail, preferably in Microsoft Word format. Authors who are unable to submit electronically should contact the associate editors to make alternative arrangements.
- Figures, tables, photographs etc. should also be submitted on disk or by email in any standard format. If this is not possible, authors should provide high quality originals in order to allow good electronic reproduction.

PREPARATION OF ARTICLES

Articles submitted should conform to the following guidelines.

- The IJT is intended for an international audience and contributors should write clearly and bear in mind that that English may not be the first language of many readers.
- Articles should not *normally* exceed 8,000 words. Tables, figures, illustrations, and references are excluded from the word count.
- The article should begin with a title page containing the title, the author's name, and affiliation followed by an abstract not exceeding 120 words and up to five keywords.
  The remainder of the article should not contain anything, which might identify the author(s).
- Contributors should indicate sources of funding, where applicable, and any restrictions on publication placed on them by sponsors.
- Contributors are responsible for obtaining permission to reproduce any material in which they do not own copyright.

Appendix 2.1: Service Improvement Project R&D Approval

Confirmation of Capacity and Capability at 2gether NHS Foundation Trust_ 17/030/2gt/SE

JN JOHNSON, Nigel (GLOUCESTERSHIRE HOSPITALS NHS FOUNDATION TRUST) <nigel.johnson1@nhs.net>

Reply all

Fri 06/10/2017, 01:36

Anna Altavilla; Anna Strudwick; +2 more

ethics CFT

Dear Anna,

Confirmation of Capacity and Capability at 2gether NHS Foundation Trust

Full Study Title: Evaluating the effectiveness of a Compassion Focused Therapy Group (CFT) that includes participants from working age and older adult services

This email confirms that 2gether Foundation Trust has the capacity and capability to deliver the above referenced study as a service evaluation.

Please do not hesitate to contact me if you have any queries and I apologise for the delay in our site providing C&C.

Kind Regards,

Nigel Johnson

Nigel Johnson| Research Governance Support Officer|Non Clinical Staff Governor|Gloucestershire Hospitals NHS Foundation Trust/2gether NHS Foundation Trust/Gloucestershire Care Services/Gloucestershire Clinical Commissioning Group

Gloucestershire Research Support Service I Leadon House I Great Western Road I Gloucestershire Royal Hospital |Gloucester| GL1 3NN

Tel: 0300 4225467(GRH 5467) I Fax: 0300 4225469

Please note my NHS email is now

Appendix 2.2: Ethical Approval from University of Bath for Service Improvement Project

Ethics 17-217

P psychology-ethics
Wed 13/09/2017, 01:02
Anna Altavilla; Anna Strudwick

Reply all

ethics CFT

You forwarded this message on 18/09/2017 23:41

Dear Anna,

Ethics 17-217 Evaluating the effectiveness of a Compassion Focused Therapy Group (CFT) that includes participants from working age and older adult services

The ethics committee have considered your ethics proposal for the study above and have given it full ethical approval.

Best wishes with your research.

Dr Nathalia Gjersoe
Chair, Psychology Research Ethics Committee

Appendix 2.3 – Service Improvement Project Interview Schedule

Interview Schedule

Research question "What are the specific elements of the group that participants find most helpful and unhelpful?"

Question 1
Have you noticed any changes in your well-being as a result of attending this group?

Question 2
Were there any particular exercises that you learnt from attending the group that you have incorporated into your life?

Optional follow-up questions:

a) What were the most helpful exercises from attending the group?
b) What were the least helpful exercises from attending the group?
c) Is there any part of the content that you think should be changed for future groups?

Question 3
What was your experience of being in a group?

Optional follow-up question:

a) What was it like listening to others experiences and sharing your own experiences in a group setting?
b) Was there anything helpful about being in a group?
c) Was there anything unhelpful about being in a group?

Question 4
Is there anything that could have been done differently to improve the experience of being in a group?

Research question "What are participants' experiences of being in a mixed age range group?"

Question 5
What was your experience of being in a mixed age range group?

Question 6
Were there any positives of being in a mixed age range group?

Question 7
Were there any negatives of being in a mixed age range group?

Optional follow-up questions:

a) Do you feel you learnt anything extra by being in a mixed age range group?
b) Do you feel you would have learnt more if you were in a similar range group?

Research Question: What are participant's experiences of having an individual session to work on their formulation of their difficulties?

Question 8
What was your experience of having an individual session to help formulate your difficulties?

Question 9
What was your understanding of this session?

Question 10
Is there anything you would have liked to have been done differently in this session?

Optional follow-up questions:

a) Was there anything helpful about this session?
b) Was there anything unhelpful about this session?

Appendix 2.4 Service Improvement Project Information Sheet

Information Sheet for taking part in Individual Interviews

Who am I?

My name is Anna Altavilla and I am a Clinical Psychologist in Training based in the Department of Psychology at the University of Bath. I am conducting this service improvement project as part of my clinical psychology doctorate.

What is this study about?

The aim of this project is to evaluate the effectiveness of the Compassionate Mind Group that you have completed. This means finding out more about your experience of taking part in this group, what you found helpful and what you found unhelpful. I am also interested in your experience of being in a mixed age range group and what your experience was of the individual formulation session. By finding out more about your experiences of the group we can then use this knowledge to improve future groups.

What would I need to do?

I would like to interview you individually about your experiences of taking part in the Compassionate Mind group. The interview will take place in a private room at Weavers Croft, Field Road, Stroud GL5 2HZ. Alternatively, if you would prefer, we can arrange the interview to take place in your home. The interview will last about 30 minutes and will take place at a time that suits you.

I have enclosed the interview questions that I plan on asking you before we meet to give you a chance to have a think about what you might like to say. There are no right or wrong answers – I just want to hear about your experience of completing the group and all feedback will be really appreciated.

After completing the interview you will be given a £5 gift voucher to thank you for taking part.

Do I have to take part?

Taking part in this research is entirely voluntary, and you are free to make your own choice about whether you want to participate. If you agree to take part you can choose not to answer any questions that you do not want to and you are free to withdraw at any time.

What will happen to the information I provide?

Should you decide to take part, the interview will be recorded. These recordings will then be typed up and the files stored on an encrypted password-protected computer. Any potentially identifying details, including your name, will be removed. The interview information will not be linked to any contact details that you provide and will be stored separately so you cannot be identified.

Once the project is completed, the information you have given to me will be kept safely by the University of Bath. If you give your consent, it may be used by other genuine researchers, with the University of Bath's approval, under the strict rules governing the confidentiality of your information. So again, your name, or any material that might identify you, will never be used or given to anyone.

What will happen to the results of this research?

What you tell me will help inform my research project on how to improve the Compassionate Minds Group. I may use extracts taken from what you have told me, however these would not identify you to anyone. The findings of the research may also be published in research journals or used in presentations. If you would like to be sent a summary of the findings, we can arrange for this.

What do I do if I would like to take part or have any more questions?

You can contact me, Anna Altavilla, to arrange a suitable time or to discuss any questions you might have.

Email – a.altavilla@bath.ac.uk Phone – TBC

You can also speak to the supervisor of the project, Dr Anna Strudwick

Email – a.strudwick@bath.ac.uk

Phone – 01225 385506 (Doctorate in Clinical Psychology Admin Office)

01453 563103 (Later Life CMHT, Weavers Croft, Field Road, Stroud GL5 2HZ)

If you have any concerns about the ethics of this research study, please contact the Bath University Psychology Department Research Executive Officer, Dr. Nathalia Giersoe

Email: psychology-ethics@bath.ac.uk Phone: 01225 38 4322

Our address is

Department of Psychology
University of Bath
Claverton Down
Bath, BA2 7AY

Appendix 2.5: Service Improvement Consent Form

CONSENT FORM

Evaluating the effectiveness of a Compassion Focused Therapy (CFT) group that includes participants from working age and older adults services

Please answer the following questions to the best of your knowledge

	YES	NO
DO YOU CONFIRM THAT YOU:		
Have participated in a Compassionate Mind Group?	☐	☐
HAVE YOU:		
☐ been given information explaining about the study?	☐	☐
☐ had an opportunity to ask questions and discuss this study?	☐	☐
☐ received satisfactory answers to all questions you asked?	☐	☐
☐ received enough information about the study for you to make a decision about your participation?	☐	☐
DO YOU UNDERSTAND: that you are free to withdraw from the study and free to withdraw your data prior to anonymisation		
☐ at any time?	☐	☐
☐ without having to give a reason for withdrawing?	☐	☐

I hereby fully and freely consent to my participation in this study

I understand the nature and purpose of the procedures involved in this study. These have been communicated to me on the information sheet accompanying this form.

I understand and acknowledge that the investigation is designed to promote scientific knowledge and that the University of Bath will use the data I provide for no purpose other than research.

I understand that the data I provide will be kept **confidential**, and that on completion of the study my data will be **anonymised** by removing all links between my name or other identifying information and my study data. This will be done by March 2018 and before any presentation or publication of my data.

I understand that the University of Bath may use the data collected for this project in a future research project but that the conditions on this form under which I have provided the data will still apply.

Participant's signature: _____ Date: _____

Name in BLOCK Letters: _____

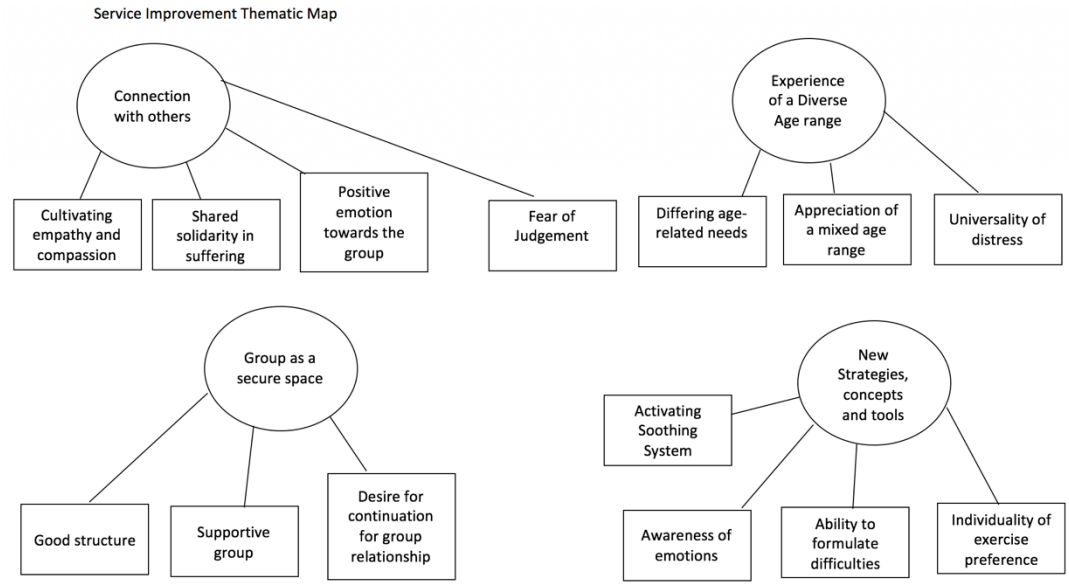
Final consent

Having participated in this study

I agree to the University of Bath keeping and processing the data I have provided during the course of this study. I understand that these data will be used only for the purpose(s) set out in the information sheet, and my consent is conditional upon the University complying with its duties and obligations under the Data Protection Act.

Participant's signature: _____ Date: _____

Appendix 2.6 Service Improvement Project Thematic Map



Appendix 2.7: Service Improvement Project Debriefing Information

Debriefing Information

Thank you for taking part in this project which has been evaluating the effectiveness of the Compassionate Minds Group in which you were a member. Your contribution is very much appreciated.

If you would like to continue learning more about compassion focused therapy the website below offers exercises, audio, video and links to books and resources related to compassion focused therapy.

https://compassionatemind.co.uk/individuals

If you would like to receive a summary of the results of the project please let us know and we can send you a summary of the findings.

Thank you again for participating. If you would like to speak to us about the project please get in touch.

Email – a.altavilla@bath.ac.uk

Phone – [redacted]

You can also speak to the supervisor of the project, Dr Anna Strudwick

Email – a.strudwick@bath.ac.uk

Phone – 01225 385506 (Doctorate in Clinical Psychology Admin Office)

01453 563103 (Later Life CMHT, Weavers Croft, Field Road, Stroud GL5 2HZ)

Our address is: Department of Psychology, University of Bath, Claverton Down Bath, BA2 7AY

.....

I confirm I have received a voucher to the value of £5 for participating in the University of Bath project 'Evaluating the Effectiveness of a Compassion Focused Therapy Group'

Signed..... Date.....

Researcher's signature..... Date.....

If you have any concerns about the ethics of this research study, please contact the Bath University Psychology Department Research Executive Officer, Dr. Nathalia Gjersoe Email: psychology-ethics@bath.ac.uk Phone: 01225 38 4322

Appendix 2.8: The British Journal of Clinical Psychology Guidelines

AUTHOR GUIDELINES

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

ONCE THE SUBMISSION MATERIALS HAVE BEEN PREPARED IN ACCORDANCE WITH THE AUTHOR GUIDELINES, MANUSCRIPTS SHOULD BE SUBMITTED ONLINE AT **http://www.editorialmanager.com/bjcp**

Click here for more details on how to use **Editorial Manager**.

All papers published in the *British Journal of Clinical Psychology* are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

DATA PROTECTION:

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at **https://authorservices.wiley.com/statements/data-protection-policy.html**.

PREPRINT POLICY:

This journal will consider for review articles previously available as preprints on non-commercial servers such as ArXiv, bioRxiv, psyArXiv, SocArXiv, engrXiv, etc. Authors may also post the submitted version of a manuscript to non-commercial servers at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

2. AIMS AND SCOPE

The *British Journal of Clinical Psychology* publishes original research, both empirical and theoretical, on all aspects of clinical psychology:

- clinical and abnormal psychology featuring descriptive or experimental studies
- aetiology, assessment and treatment of the whole range of psychological disorders irrespective of age group and setting
- biological influences on individual behaviour
- studies of psychological interventions and treatment on individuals, dyads, families and groups

For specific submission requirements, please view the **Author Guidelines**.

The Journal is catholic with respect to the range of theories and methods used to answer substantive scientific problems. Studies of samples with no current psychological disorder will only be considered if they have a direct bearing on clinical theory or practice.

The following types of paper are invited:

- papers reporting original empirical investigations;
- theoretical papers, provided that these are sufficiently related to empirical data;

- review articles, which need not be exhaustive, but which should give an interpretation of the state of research in a given field and, where appropriate, identify its clinical implications;
- Brief Reports and Comments.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Articles should be no more than 5000 words (excluding the abstract, reference list, tables and figures) and any papers that are over this word limit will be returned to the authors. Appendices are included in the word limit; however online appendices are not included.

In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.

Please refer to the separate guidelines for **Registered Reports**.

All systematic reviews must be pre-registered.

4. PREPARING THE SUBMISSION

Contributions must be typed in double spacing. All sheets must be numbered.

Cover Letters

Cover letters are not mandatory; however, they may be supplied at the author's discretion. They should be pasted into the 'Comments' box in Editorial Manager.

Parts of the Manuscript

The manuscript should be submitted in separate files: title page; main text file; figures/tables; supporting information.

Title Page

You may like to use **this template** for your title page. The title page should contain:

i. A short informative title containing the major key words. The title should not contain abbreviations (see Wiley's best practice SEO tips);
ii. A short running title of less than 40 characters;
iii. The full names of the authors;
iv. The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
v. Abstract;
vi. Keywords;
vii. Practitioner Points;
viii. Acknowledgments.

Appendix 3.1 Main Research Project HRA Ethical Approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Miss Anna Altavilla
Trainee Clinical Psychologist
Taunton and Somerset NHS Trust
University of Bath
Department of Clinical Psychology
10 West Claverton Down
BA2 7AY

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

08 October 2018

Dear Miss Altavilla

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Exploring the impact of recalling a nostalgic memory in comparison to an ordinary memory on how people relate to their dementia and death anxieties**
IRAS project ID:	**241675**
Protocol number:	**N/A**
REC reference:	**18/WM/0257**
Sponsor	**University of Bath**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

Appendix 3.2: Main Research Project: University of Bath Ethical Approval

From: psychology-ethics
Sent: 19 October 2018 15:29
To: Anna Altavilla
Subject: Ethics 18-259: approval

Dear Anna,

Ethics code 18-259: Exploring if past memories affect how people relate to their dementia

Sorry for a bit slow response - I am happy to confirm that you have received full ethical approval from the University of Bath Department of Psychology Ethics Committee for your application via Chair's Action. Please use the code 18-259 as proof of ethical approval on internal documentation.

Please be aware that it is your responsibility to let us know as soon as possible if any issues or complaints of an ethical nature arise over the course of your research.

Best of luck with your research,
Jie

Dr. Jie Sui
Chair, Psychology Ethics Committee

Appendix 3.3: Main Research Project Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Exploring if past memories affect how people relate to their dementia

We are inviting people who have recently been diagnosed with dementia to take part in our research study. Before you decide to take part, it is important for you to understand why we are doing this study.

Please take the time to read this information and discuss with friends and family if you wish.

Why are we doing this research?

Dementia can have a large emotional impact on a person's identity and well-being. We are interested in understanding how to help people affected by dementia manage this emotional impact. Previous studies have found that recalling certain types of past memories can improve how people feel about themselves, such as increasing self-esteem. This study aims to investigate if recalling past memories will impact on your thoughts about your own dementia and anxieties or worries you may have about death. The results of this study will help us develop new ways to support people affected by dementia to manage the emotional impact.

Why have I been invited?

You have been invited to take part because you have been diagnosed with dementia following an assessment from an NHS memory service.

Do I have to take part?

No. Your participation in this study is entirely voluntary. Taking part in this study is separate from your treatment and care. Your treatment will not be affected in any way by deciding to take part or not. If you decide not to carry on with the study or want to withdraw you will be able to and this will not affect your treatment and care in anyway.

What would taking part involve?

The study will involve a number of tasks which will take roughly 1 hour to complete.

First, we will ask you some questions about your mood. We will then ask you to remember an event from the past. You will then complete questionnaires covering a range of topics including how you are feeling, a questionnaire asking you to agree or disagree about statements about the impact of dementia and a questionnaire asking you to agree or disagree with statements that include worries or concerns that people can have about death.

We can come to your home or you can come into your local clinic to take part, whichever is easiest for you.

What are the possible benefits of taking part?

You will be adding to scientific knowledge about dementia and new ways to support people with dementia. Without volunteers like you research of this kind would not be possible. Your

participation and contribution is invaluable. As a thank-you for your time we will give you a £5 Amazon voucher for taking part in the study.

What are the possible disadvantages of taking part?

We do not feel that there are many disadvantages to taking part. Some of the questionnaires ask you to agree or disagree with statements about the impact of having dementia. Another questionnaire asks you to agree or disagree with statements about worries or concerns about death. There is a possibility that you may find these topics upsetting.

If you feel that questionnaires covering these topics may be too difficult or upsetting for you at this time, we recommend that you do not take part in this study at this time. However, if you do still wish to take part you will be supported through the process, and you do not have to answer any questions that you don't want to. After the study has finished we will give you more information about the study and there will be an opportunity to discuss how you are feeling in a supportive way. There will also be an opportunity to watch a clip from a comedy show if you wish.

Should you feel distressed following your participation then contact Anna Altavilla, Clinical Psychologist in Training, Chief Investigator of the project. Alternatively, you can contact Dr Anna Strudwick, Clinical Psychologist or Professor Richard Cheston whose details are at the bottom of this sheet.

If you have been recruited from the Join Dementia Research Register or have not had a recent cognitive assessment in the last 6 months, we will do a brief cognitive screening test called the MOCA to check your eligibility into this study. We are recruiting people with mild dementia so if you score less than 12 on this screening you would unfortunately would not be able to take part. If this raises concerns for you we can provide a supporting letter to be sent to your GP and local memory service explaining our role in the research, the concerns that have been raised and outlining the results of the assessment.

Who will have access to my medical records?

Provided you agree, the clinician at your memory service will share relevant details about your dementia and recent assessments from your medical records that are directly related to this study with the researcher (Anna Altavilla) and her supervisors in order to check that you are eligible to take part. If you have registered on the Join Dementia Register, then we will take this information from the statements that you made when you enrolled and by conducting a brief memory screening assessment (the MOCA).

What if there is a problem?

If you have any concerns or wish to complain about any aspect of this project, you should initially contact the researcher, Anna Altavilla, who will do her best to address your concerns. Her contact details are provided at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting, the University of Bath Secretary Mark Humphries on 01225 286212 or universitysec@bath.ac.uk. The University of Bath, as Sponsor of the study, has indemnity (insurance) arrangements in place. Every care will be taken to ensure your wellbeing during the course of this project.

What happens with my information?

All data collected during the study will be anonymised. This means that you will be given a participant number and all the data you provide will be linked to that number rather than to any information that could identify you such as your name, age or gender. A list linking your study number with your name will be kept by the researcher in a password-protected file and will not be accessed by anyone else. Data collected as part of this study will be kept securely for a minimum period of ten years after the end of the study after which time it will be destroyed. The data retained during this period will be anonymous.

What will happen to the findings of the project?

The results will be published in peer-reviewed journals. You will not be able to be identified in any published results. If you decide you would like to be sent information, then please let the researcher know. We can send you a summary of the results and/or a copy of published papers if you chose by completing the appropriate box on the consent form. In order to do this, the researcher will keep a secure record of your contact details (your name and address) and will send you the information once all data is collected and analysed after which your details will be deleted.

Further information about General Data Protection Regulation (GDPR)

University of Bath is the sponsor for this study based in England. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. University of Bath will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at
https://www.bath.ac.uk/guides/data-protection-guidance/

Your NHS trust will use your name, NHS number and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from University of Bath and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Your NHS trust will pass these details to University of Bath along with the information collected from you and/or your medical records. The only people in University of Bath who will have access to information that identifies you will be people who need to contact you to take part in the study or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details.

Your NHS trust will keep identifiable information about you from this study for 10 years after the study has finished.

Appendix 3.4: Main Research Project Informed Consent

UNIVERSITY OF BATH

Version 2, 20/09/18

Centre Number:

IRAS Project ID: 241675

Patient Identification Number for this trial:

CONSENT FORM

Title of Project: Exploring if past memories affect how people relate to their dementia

Name of Researcher: Anna Altavilla (Clinical Psychologist in training)

Please initial box

1. I confirm that I have read and understand the information sheet dated 16/09/18 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I agree for the researcher (Anna Altavilla) and her supervisors to have access to the information produced from my responses for the purposes of this study ☐
4. I am aware that the results of the study may be presented in research reports, scientific conferences and/or journals. However, the information I provide for the study will remain confidential. ☐
5. I understand that relevant sections of my medical notes, such as details about my dementia and any cognitive assessments undertaken will be shared with the researcher (Anna Altavilla) and her supervisors in order to assess eligibility. I give permission for these individuals to have this information from my records. ☐
6. I agree for my data to be stored anonymously and that any published quotations or extracts from the research will maintain my confidentiality. ☐
7. I agree to my data being securely stored by the University of Bath for a minimum of 10 years. The data that is retained is anonymous. ☐
8. I agree to my study data and/or medical records being accessed by the Sponsor and regulatory authorities for monitoring and auditing purposes ☐

9. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Person taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file.

Appendix 3.5 Main Research Project: Measures

Exploring if past memories affect how people relate to their dementia

1. Informed Consent ☐ tick completed

Participant Number:

2. PARTICIPANT DEMOGRAPHICS

1. Has informed consent been obtained? *(Please circle)*	Y / N If no STOP and obtain consent before proceeding	
	2. Date of consent: ___ /___ / ____	
3. Date of birth: ___ /___ / ____	4. Gender: Male / Female	
5. Living circumstances: *(Please circle)*	A Living alone C Living with other family E Residential care	B Living with partner/spouse D Sheltered accommodation
6. Date diagnosis given: ___ /___ / ____	7. Research Appointment: Clinic / Home	
8. Diagnosis: *(Please circle)*	A Alzheimer's Disease C Mixed form of these	B Vascular Dementia D other (*please specify*)
9. MOCA score or equivalent (eg MMSE, ACE-R, ACE-III)		10. Date of MOCA (or equivalent) ___ /___ / ____

11. Ethnicity: *(Please circle)*

White A British B Irish C Any other White background	**Mixed** D White and Black Caribbean E White and Black African F White and Asian G Any other mixed background

Asian or Asian British H Indian J Pakistani K Bangladeshi L Any other Asian background	**Black or Black British** M Caribbean N African P Any other Black background
Other Ethnic Groups R Chinese S Any other ethnic group Z Not stated	

3) MOCA (if applicable) ☐ tick completed

4) THE GERIATRIC ANXIETY INVENTORY

Please answer the items according to how you've felt in the last week

1	I worry a lot of the time.	Agree/Disagree
2	I find it difficult to make a decision.	Agree/Disagree
3	I often feel jumpy.	Agree/Disagree
4	I find it hard to relax.	Agree/Disagree
5	I often cannot enjoy things because of my worries.	Agree/Disagree
6	Little things bother me a lot.	Agree/Disagree
7	I often feel like I have butterflies in my stomach.	Agree/Disagree
8	I think of myself as a worrier.	Agree/Disagree
9	I can't help worrying about even trivial things.	Agree/Disagree
10	I often feel nervous.	Agree/Disagree
11	My own thoughts often make me anxious.	Agree/Disagree
12	I get an upset stomach due to my worrying.	Agree/Disagree
13	I think of myself as a nervous person.	Agree/Disagree
14	I always anticipate the worst will happen.	Agree/Disagree
15	I often feel shaky inside.	Agree/Disagree
16	I think that my worries interfere with my life.	Agree/Disagree
17	My worries often overwhelm me.	Agree/Disagree
18	I sometimes feel a great knot in my stomach.	Agree/Disagree
19	I miss out on things because I worry too much.	Agree/Disagree
20	I often feel upset.	Agree/Disagree
	Number of 'agrees' circled	

5. THE GERIATRIC DEPRESSION SCALE* – 15 ITEM

Please complete with the participant

1	Are you basically satisfied with your life?	Yes/**No**
2	Have you dropped many of your activities and interests?	**Yes**/No
3	Do you feel that your life is empty?	**Yes**/No
4	Do you often get bored?	**Yes**/No
5	Are you in good spirits most of the time?	Yes/**No**
6	Are you afraid that something bad is going to happen to you?	**Yes**/No
7	Do you feel happy most of the time?	Yes/**No**
8	Do you often feel helpless?	**Yes**/No
9	Do you prefer to stay at home, rather than going out and doing new things?	**Yes**/No
10	Do you feel you have more problems with memory than most?	**Yes**/No
11	Do you think it is wonderful to be alive now?	Yes/**No**
12	Do you feel pretty worthless the way you are now?	**Yes**/No
13	Do you feel full of energy?	Yes/**No**
14	Do you feel that your situation is hopeless?	**Yes**/No
15	Do you think that most people are better off than you are?	**Yes**/No
	Number of bold statements circled	

* Sheikh JI, Yesavage JA: Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. Clinical Gerontology : A Guide to Assessment and Intervention 165-173, NY: The Haworth Press, 1986.

6. THE POSITIVE AND NEGATIVE AFFECT SCHEDULE

This scale consists of a number of words that describe different feelings and emotions. Read each item and then list the number from the scale below next to each word. Indicate to what extent you feel this way right now, that is, at the present moment.

1	2	3	4	5
Very slightly or not at all	A little	moderately	Quite a bit	extremely

_____ 1. Interested	_____ 11. Irritable
_____ 2. Distressed	_____ 12. Alert
_____ 3. Excited	_____ 13. Ashamed
_____ 4. Upset	_____ 14. Inspired
_____ 5. Strong	_____ 15. Nervous
_____ 6. Guilty	_____ 16. Determined
_____ 7. Scared	_____ 17. Attentive
_____ 8. Hostile	_____ 18. Jittery
_____ 9. Enthusiastic	_____ 19. Active
_____ 10. Proud	_____ 20. Afraid

7 PAST MEMORY RECALL ACTIVITY – see instruction sheet

8. MANIPULATION CHECK

After thinking about the experience/ event, please use the following scale to record your answer:

1. Right now, I am feeling quite nostalgic

1	2	3	4	5	6
Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree

2. I am having nostalgic feelings

1	2	3	4	5	6
Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree

3. I feel nostalgic at the moment

1	2	3	4	5	6
Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree

9. The Representations and Adjustment Index (RADIX)

Representations and Adjustment Index (RADIX)

Catherine Quinn, Robin Morris, Linda Clare

Did the person answer 'yes' to one or more questions in the screening checklist? No Yes

Was the RADIX administered? No Yes

Dementia Representations Profile

Please use this section to record a summary of the person's responses to the questions

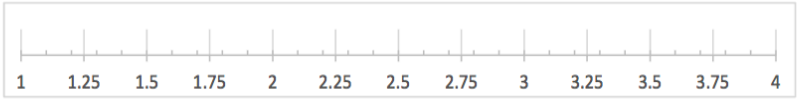
1. IDENTITY: _____

2. DIAGNOSTIC IDENTITY: _____

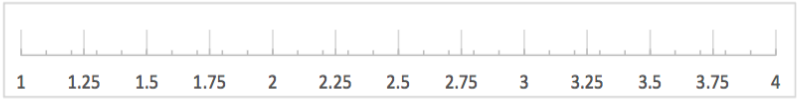
3. CAUSE: _____

4. TIMELINE:	GET BETTER	STAY SAME	GET WORSE	UNSURE
5. POSSIBLE TO CONTROL:	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE

6. PRACTICAL CONSEQUENCES MEAN SCORE:



7. EMOTIONAL CONSEQUENCES MEAN SCORE:



SECTION 1: SCREENING CHECKLIST

I would like to talk to you about any changes that you have been experiencing.

1. Have you, a family member or doctor noticed that you have been having difficulty with concentration?

No Yes

2. Have you, a family member or doctor noticed that you have been forgetful?

No Yes

3. Have you, a family member or doctor noticed that you have been having difficulty with remembering (e.g. recent events)?

No Yes

4. Have you, a family member or doctor noticed that you have been having difficulty with thinking?

No Yes

5. Have you, a family member or doctor noticed that you have been having difficulty with your ability to say what you want to say?

No Yes

6. Have you, a family member or doctor noticed that you have been having difficulty with your ability to manage your day-to-day activities?

No Yes

7. Have you, a family member or doctor noticed that you have been having difficulty with planning ahead?

No Yes

8. Have you, a family member or doctor noticed that you have been having difficulty with making decisions?

No Yes

9. Are you different in some way to how you used to be?

No Yes

Instructions for the researcher: Did the participant identify one or more changes? No Yes

If **YES** you can continue with the RADIX

SECTION 2: RADIX

10. What do you call [this difficulty/these difficulties, or condition] that you have?

_____

_____

11. Are you aware of a specific diagnosis? What does the doctor call it?

_____

_____

Instructions for the researcher: Record the person's label for the condition. How does s/he refer to the condition; does s/he call it dementia or something else e.g. short-term memory problems, forgetfulness. Use this term, referred to as [identity label] in all subsequent questions. If the participant does not give a label, replace [identity label] with "condition" or "difficulties" instead.

_____

_____

POSSIBLE CAUSES OF MEMORY DIFFICULTIES

12. What do you think caused or causes your [identity label]?

_____

_____

a) Instructions for the researcher: If no instant response then follow up with: **These are some of the things that other people say causes their problems; which one do you think applies to you?**

Instructions for the researcher: Please cross all that the participant says applies to him/her.

- ☐ Ageing
- ☐ Changes within the brain (e.g. something in your brain dies off)
- ☐ Illness or disease or physical condition (e.g. diabetes)
- ☐ Hereditary condition (e.g. genetics)
- ☐ Lifestyle/life events (e.g. stress, bereavement)
- ☐ Don't know (record if given as a spontaneous response)

b) Instructions for the researcher: If more than one cause identified, ask him/her to nominate the most important one and cross the appropriate box below:

- ☐ Ageing
- ☐ Changes within the brain (e.g. something in your brain dies off)
- ☐ Illness or disease or physical condition (e.g. diabetes)
- ☐ Hereditary condition (e.g. genetics)
- ☐ Lifestyle/life events (e.g. stress, bereavement)
- ☐ Don't know (record if given as a spontaneous response)

DURATION OF THESE CHANGES *(Timeline)*

13. What do you think will happen to your [identity label] over time? Will it/they

Get better (1) Stay the same as it is now (2) Get worse (3) Unsure (4)

CONSEQUENCES OF THESE CHANGES

Please indicate how much you agree or disagree with the following statements. There are no "right" or "wrong" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

Control

14. There is a lot which I can do to control the effects of my [identity label]
Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

Practical Consequences

15. As a result of my [identity label] people treat me differently
Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

16. As a result of my [identity label] I do not go out as much as I used to
Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

17. As a result of my [identity label] I cannot do some of the things that I used to do
Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

18. As a result of my [identity label] I feel I have lost control over my life
Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

TO GENERATE MEAN SCORE: First record the TOTAL score (SUM of Q15~Q18):_____
Second divide (÷) the TOTAL score by 4= _____ This generates the MEAN SCORE

Emotional Consequences

19. As a result of my [identity label] I get annoyed or frustrated with myself
Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

20. As a result of my [identity label] I get very angry about what is happening to me
Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

21. As a result of my [identity label] I feel I have lost confidence in myself
Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

22. I feel low or upset when I think about my [identity label]
Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

23. I find myself worrying about my [identity label]
Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

TO GENERATE MEAN SCORE: First record the TOTAL score (SUM of Q19~Q23):_____
Second divide (÷) the TOTAL score by 5= _____ This generates the MEAN SCORE

10.REMINDER OF THE MEMORY

Participant to recall their chosen memory (see instruction sheet) ☐ tick completed

11.THREAT OF DEMENTIA SCALE

Bristol Threat of Dementia (TODS) Scale

Please read the following statements, all of which are symptoms of dementia or Alzheimer's Disease. Imagine that these descriptions are real, and that they apply to you. Please rate the extent to which your sense of well-being would be threatened by each statement

		The extent to which I would feel threatened is:						
		Not at all						**Very much**
	Question	**1**	**2**	**3**	**4**	**5**	**6**	**7**
1	**Your illness may mean that you will find it hard to follow conversations**							
2	**Your illness means that your symptoms will tend to become more severe**							
3	**As a result of the illness you may have problems reasoning**							
4	**Your illness will mean that you cannot always remember things you have heard**							
5	**You may forget and carry out the same activity twice**							

6	**You may forget and ask the same question over and over**							

7	**People with your illness can become confused about the time**							
8	**The illness will cause you to struggle to remember recent events**							
9	**With the illness you will notice that you sometimes lose track of what you are saying**							
10	**As a result of the illness you may misinterpret the world around you**							
11	**The symptoms of your illness can develop gradually over many months**							
12	**The illness means that you may forget the names of friends or family**							
13	**Your illness may make you confused at times**							

12.REMINDER OF THE MEMORY

Participant to recall their chosen memory (see instruction sheet) ☐ tick completed

13.Death Anxiety Scale

Please read the following statements and then circle the number of the response that best describes how you feel about the item.

Questions					
1. I am very much afraid to die	1 Strongly Agree	2 Agree	3 Neither	4 Disagree	5 Strongly Disagree
2. The thought of death seldom enters my mind	1 Strongly Agree	2 Agree	3 Neither	4 Disagree	5 Strongly Disagree
3. It doesn't make me nervous when people talk about death	1 Strongly Agree	2 Agree	3 Neither	4 Disagree	5 Strongly Disagree
4. I dread to think about having an operation	1 Strongly Agree	2 Agree	3 Neither	4 Disagree	5 Strongly Disagree
5. I'm not at all afraid to die	1 Strongly Agree	2 Agree	3 Neither	4 Disagree	5 Strongly Disagree
6. I am not particularly afraid of getting cancer	1 Strongly Agree	2 Agree	3 Neither	4 Disagree	5 Strongly Disagree
7) The thought of death never bothers me	1 Strongly Agree	2 Agree	3 Neither	4 Disagree	5 Strongly Disagree

8) I am often depressed by the way time flies so rapidly	(1) Strongly Agree	(2) Agree	(3) Neither	(4) Disagree	(5) Strongly Disagree
9) I fear dying a painful death	(1) Strongly Agree	(2) Agree	(3) Neither	(4) Disagree	(5) Strongly Disagree
10) The subject of life after death troubles me greatly	(1) Strongly Agree	(2) Agree	(3) Neither	(4) Disagree	(5) Strongly Disagree
11) I am really scared of having a heart attack	(1) Strongly Agree	(2) Agree	(3) Neither	(4) Disagree	(5) Strongly Disagree
12) I often think about how short life really is	(1) Strongly Agree	(2) Agree	(3) Neither	(4) Disagree	(5) Strongly Disagree
13) I shudder when I hear people talking about a world war III	(1) Strongly Agree	(2) Agree	(3) Neither	(4) Disagree	(5) Strongly Disagree
14) The sight of a dead body is horrifying to me	(1) Strongly Agree	(2) Agree	(3) Neither	(4) Disagree	(5) Strongly Disagree

15) I feel like that the future holds nothing for me to fear	① Strongly Agree	② Agree	③ Neither	④ Disagree	⑤ Strongly Disagree

14. THE POSITIVE AND NEGATIVE AFFECT SCHEDULE

This scale consists of a number of words that describe different feelings and emotions. Read each item and then list the number from the scale below next to each word. Indicate to what extent you feel this way right now, that is, at the present moment.

1	2	3	4	5
Very slightly or not at all	A little	moderately	Quite a bit	extremely

_____ 1. Interested

_____ 2. Distressed

_____ 3. Excited

_____ 4. Upset

_____ 5. Strong

_____ 6. Guilty

_____ 7. Scared

_____ 8. Hostile

_____ 9. Enthusiastic

_____ 10. Proud

_____ 11. Irritable

_____ 12. Alert

_____ 13. Ashamed

_____ 14. Inspired

_____ 15. Nervous

_____ 16. Determined

_____ 17. Attentive

_____ 18. Jittery

_____ 19. Active

_____ 20. Afraid

15.Debriefing - ☐ tick completed

16.Payment of voucher - ☐ tick completed

Appendix 3.6 Ordinary Memory Instructions

PAST MEMORY INSTRUCTIONS:

*"According to the New Oxford Dictionary, 'an **ordinary** event is an event with no special or distinctive features'. Please bring to mind an **ordinary** event in your life. Specifically, try to think of a past event that is **ordinary**. Bring this **ordinary** experience to mind. Immerse yourself in the **ordinary** experience. How does it make you feel? Please spend 2minutes thinking about how it makes you feel. Please describe this **ordinary** event (i.e., describe the experience)".*

RECALL OF PAST MEMORY INSTRUCTIONS

"Please can you recall the ordinary memory you described to me earlier"

For participants randomised to Nostalgic memory condition:

Appendix 3.7 Nostalgic Memory Instructions

PAST MEMORY INSTRUCTIONS:

*"According to the New Oxford Dictionary, '**nostalgia**' is defined as a 'sentimental longing for the past.' Please think of a **nostalgic event** in your life. Specifically, try to think of a past event that makes you feel **most nostalgic**. Bring this **nostalgic** experience to mind. Immerse yourself in the **nostalgic** experience. How does it make you feel? Please spend **2minutes** thinking about how it makes you feel. Please describe this **nostalgic** event (i.e., describe the experience)".*

RECALL OF PAST MEMORY INSTRUCTIONS

"Please can you recall the nostalgic memory you described to me earlier"

UNIVERSITY OF BATH

DEBRIEF SHEET

Exploring if past memories affect how people relate to their dementia

Some people who are affected by dementia can find it difficult to recognise the consequences of their illness. This may be because of their illness, or it may be because dementia is frightening and people prefer not to think about it. Whatever the causes, there are a number of knock-on effects to this lack of awareness. These can include psychological problems and a decreased ability to function effectively on a day-by-day basis. It can also have a negative effect on the people around them. Some people affected by dementia can often understandably feel threatened by it and worried about death and we were interested in looking at ways that can have reduce this threat and worries.

This study looks at whether we can help people recognise the consequences of their dementia, reduce how threatened they feel about dementia symptoms and reduce how anxious they may feel about death by increasing psychological resources such as self-esteem, meaning in life and feeling socially connected to others. Previous research has shown that one potential way we can increase these resources is by asking people to recall a nostalgic memory. This seems to be because nostalgia increases self-esteem, social connectedness and meaning in life in a way that other memories don't.

Today, you took part in a number of tasks. Firstly, you were randomly assigned to bring to mind either an ordinary memory from your past or a nostalgic memory. This was done using a computer programme and we had no control over it. It was also not done on the basis of any of your characteristics. This meant that everyone had an equal chance of either being asked to remember an ordinary memory or a nostalgic memory. We did this because we were testing to see if those who remembered a nostalgic memory were able to recognise the consequences of their dementia, feel less threatened by dementia symptoms and feel less anxious about death compared to those who remembered an ordinary memory.

Remember, your data are treated as confidential. Results of this research will not include your name or any other identifying characteristics. We would be happy to send you a summary of the results if you would like.

By carrying out this research, we hope to be able to develop more effective ways to help people with dementia feel less threatened about their illness.

If you have been adversely affected or distressed in any way by any aspect of this study, then please contact the researcher in the first instance; Anna Altavilla, Clinical Psychologist in Training a.altavilla@bath.ac.uk. Alternatively, you can contact Dr Anna Strudwick, Clinical Psychologist a.strudwick@bath.ac.uk

If you would like more information about Alzheimer's disease and dementia, then the best way to do so is on-line at http://www.alzheimers.org.uk/. The Alzheimer Society Helpline (0300 222 11 22) is also open from 9am to 5pm Monday to Friday and on Saturday and Sunday from 10am to 4pm.

Contact Information

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Appendix 3.7: Main Research Project: Dealing with Distress Protocol

Protocol for working with participants who are distressed

1. All data collection will be conducted by the researcher/Principle Investigator, Anna Altavilla. Anna is a Clinical Psychologist in Training in her second year who has completed a 6-month older adult placement and the associated teaching (six months). Anna has worked with older adults with dementia for two years as an Assistant Psychologist prior to commencing the doctorate which involved both assessment and therapy (groups and individual). The 6-month teaching block has included training on working therapeutically with those impacted by dementia and how to therapeutically manage distress.
2. Anna Altavilla is supervised by Dr Anna Strudwick (internal supervisor) and Professor Richard Cheston (external supervisor). Dr Strudwick is an Older Adult Clinical Psychologist with expertise and extensive experience with working therapeutically with older adults and dementia. Professor Richard Cheston has provided individual, couple and group psychotherapy for people affected by dementia within NHS and other settings for over 20 years during which time he has been involved in research projects and has written on these techniques. He is a Consultant Clinical Psychologist, a qualified Group Analytic therapist and a recognised authority on the use of therapy in this area.
3. During the course of data collection, Anna Altavilla will meet at least monthly with Dr Anna Strudwick who will provide supervision on both the research aspects of the work and any relevant clinical elements. Dr Strudwick will also be available to provide any additional supervision if any specific issue arises. Anna Altavilla will also be in monthly email contact with Professor Cheston to provide updates on the data collection and also for any further supervision on the research and clinical elements if required.
4. In the event of a participant becoming distressed during the course of the research, Anna Altavilla will interrupt the research process and provide appropriate emotional support to the participant. She will offer the participant the option of either pausing, or ending data collection.
5. In the event of the participant becoming distressed after the research has finished, Anna Altavilla will offer appropriate emotional support. The participant information sheet provides details of Anna Altavilla, Dr Anna Strudwick and Professor Richard Cheston who the participant may contact in the unlikely event of feeling distressed after participating.
6. Anna Altavilla will also assess any additional needs they may require and signpost them to the appropriate support. For example, this could be longer-term follow-up either within primary or secondary care and seeking consent from him or her to inform their GP. Anna Altavilla will seek supervision from Dr Anna Strudwick and/or Professor Richard Cheston in the event of this occurring.

7. In the event of a participant becoming distressed due to having concerns regarding a decline in cognitive function that is greater that they expected, Anna Altavilla will provide them with emotional support. Should the individual wish, a supporting letter from the researcher can also be directly sent to the GP and their local memory service, explaining their role in the research, the concerns that have been raised and outlining the results of the assessment. Anna Altavilla will seek supervision from Dr Anna Strudwick and/or Professor Richard Cheston in the event of this occurring.
8. All participants will be provided with an information sheet and debrief sheet which has contact details for Anna Altavilla, Dr Anna Strudwick and Professor Richard Cheston.
9. The debrief sheet will also provide phone number of the Alzheimer Society helpline. This is open from 9am to 5pm Monday to Friday and on Saturday and Sunday from 10am to 4pm.

Preparation of manuscripts

Research Reports

Organization and style of presentation

- Manuscripts must be written in US English. Authors whose native language is not English are recommended to seek the advice of a native English speaker or English language service before submitting their manuscripts. A language or editing service that we recommend is PeerWith.
- Nomenclature for amyloids should follow the 2018 guidelines of the International Society of Amyloidosis (ISA) nomenclature committee (*Amyloid* **25**, 215-219, 2018), e.g., amyloid-β (Aβ) and amyloid-β protein precursor (AβPP). Also preferred is $A\beta_{42}$ and sAβPPα.
- Manuscripts should be double spaced throughout with wide margins (2.5 cm or 1 in), including the abstract and references. Every page of the manuscript, including the title page, references, tables, etc., should include a page number centered at the bottom. Do not number headings or subheadings (use all caps, italics, then underline). Footnotes should be avoided.
- There are no page or word limits for Research Reports but manuscripts over 10,000 words (Introduction through Discussion) should be approved by the Editor-in-Chief before submission.
- Manuscripts should be organized in the following order with headings and subheadings typed on a separate line, without indentation.

Title page

- Title (should be clear, descriptive, concise, and avoid the use of abbreviations)
- Full name(s) of author(s)
- Full affiliation(s). Delineate affiliations with lowercase letters.
- Present address of author(s), if different from affiliation
- Running title (45 characters or less, including spaces)
- Complete correspondence address, including telephone number and e-mail address

Authorship

To be considered as an author of an article, the following criteria must be met:

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

When submitting the manuscript, the author listing and order should be final. If any addition, deletion, or rearrangement of author names in the authorship list does need to be made after submission, this can be done only before acceptance and with the Editor's approval. To request such a change, the Editor must receive the following from the corresponding author: (1) the reason

for the change in author list and (2) written confirmation from all authors, including the affected author, that they agree with the addition, removal, or rearrangement. Only in exceptional circumstances will the Editor consider the addition, deletion, or rearrangement of authors after the manuscript has been accepted. While the Editor considers the request, publication of the manuscript will be suspended. If the manuscript has already been published in an issue, any requests approved by the Editor will result in an Erratum. Please contact the Managing Editor (editorial@j-alz.com) for more information.

Abstract and Keywords

- The abstract should be clear, descriptive, self-explanatory, and no longer than 250 words.
- If a structured abstract is desired, the following must be included: Background, Objective, Methods, Results, and Conclusion.
- Do not include references in the abstract.
- Include a list of 4-10 keywords. These keywords should be terms from the MeSH database.
- Note that ALL articles (except book reviews and letters to the editor) must include an abstract.

Introduction

Provide enough information to put your work into context. Be concise. Clearly address the following points:

- What information is already available?
- What is the rationale or reason for your research?
- What problem(s) does it address?

Do not include a comprehensive literature review of your research. End the Introduction by clearly stating the aims of your study.

Materials and Methods

This section should be well structured and detailed enough for others to be able to reproduce your experiments. Use clear sub-headings throughout. Start by describing the materials use, the supplier source, including any relevant catalog information, and supplier location. Use references appropriately to refer to published protocols or methodology. Do not repeat a detailed description of an already-published method or protocol.

Results

This section should present the results and summarize the findings of your study. Do not provide any data in great detail. If you need to include additional detailed data, do so in supplementary files submitted with the paper. Consider providing a one-sentence summary at the beginning of each paragraph in the Results section, if you think that this would help the reader in understanding your findings.

Discussion

Begin this section with a brief summary of the main findings. Ensure that you answer all the questions posed in the Introduction. Mention both the strengths and the limitations for your study, as well as applications and implications of your findings. Compare these to other published findings.

Acknowledgments (including sources of support)

Include individuals or companies which have assisted with your study, including advisors, funding sources, administrative support and suppliers who may have donated or given materials used in the study.

Conflict of Interest/Disclosure Statement

If there is no conflict of interest to declare, do still include this section and insert "The authors have no conflict of interest to report". If the article is accepted, this section will be replaced by a link to the online disclosures which must be completed by all authors. See our policy on Financial Disclosure for more information.

References (Download the EndNote style from EndNote (https://endnote.com/style_download/journal-of-alzheimers-disease/). A .csl file is available here.)

1 Place citations as numbers in square brackets in the text in order of appearance. Each citation should be to one manuscript only. All publications cited in the text should be presented in a list of references following the text of the manuscript. Only articles published or accepted for publication should be listed in the reference list. Submitted articles can be listed in the text as (Author(s), unpublished data).

2 All authors should be listed in the reference list.

3 Please include doi numbers for "in press" articles if available.

4 References should be listed in the order of appearance in the following style:

[1] Alzheimer Research Forum, Drugs in Clinical Trials: AAB-001, http://www.alzforum.org/drg/drc/detail.asp?id=101, Last updated May 29, 2007, Accessed on January 29, 2008.

[2] Smith MA (2006) Oxidative stress and iron imbalance in Alzheimer disease: how rust became the fuss! In *Alzheimer's Disease: A Century of Scientific and Clinical Research*, Perry G, Avila J, Kinoshita J, Smith MA, eds. IOS Press, Amsterdam, pp. 305-308.

[3] Hara H, Monsonego A, Yuasa K, Adachi K, Xiao X, Takeda S, Takahashi K, Weiner HL, Tabira T (2004) Development of a safe oral Abeta vaccine using recombinant adeno-associated virus vector for Alzheimer's disease. *J Alzheimers Dis* **6**, 483-488.

[4] Paxinos G, Watson C (1986) *The Rat Brain in Stereotaxic Coordinates*, Academic Press, Sydney.

[5] Zhu X, Perry G, Smith MA (2004) Two hits and you're out? A novel mechanistic hypothesis of Alzheimer disease, *Alzheimer Research Forum*, http://www.alzforum.org/res/adh/cur/zhu/default.asp, Posted 23 October 2004, Accessed 29 January 2008.

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Datasets and Data Articles

- All datasets and data articles referenced in your manuscript should be cited in the main reference list of your article (not in a separate box or in the article text).

Tables

- Number according to their sequence in the text. The text should include references to all tables.
- Provide each table on a separate page of the manuscript after the references.
- Tables should be in an editable format (not inserted as pictures).
- Include a brief and self-explanatory title with any explanations essential to the understanding of the table given in footnotes at the bottom of the table.
- Vertical lines should not be used to separate columns. Leave some extra space between the columns instead.
- Citations in the tables should be numbered and included in the Reference list.

Figure Legends/Figures

- Number the figures according to their sequence in the text. The text should include references to all figures.
- Each figure should be provided on a separate page, not included in the text.
- Figures should preferably be formatted in TIF or EPS format. JPG is also acceptable.
- Composite figures MUST be preassembled.
- Figures should be designed with the format of JAD in mind. They should be of such a size as to allow a reduction of 50%.
- Line art should have a minimum resolution of 1200 dpi and be saved as an EPS or TIF.
- Do not use faint lines and/or lettering and check that all lines and lettering within the figures are legible at the final size.
- All lines should be at least 0.1 mm (0.3 pt) wide.
- Vector graphics containing fonts must have the fonts embedded in the files.
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- Do not save figures as JPG; this format may lose information in the publishing process.
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- Do not use color in your figures if they are to be printed in black & white, as this will reduce the print quality (note that in software often the default is color; this can be changed in the settings).
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- Photographs are only acceptable if they have good contrast and intensity.
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- Costs for color figures in the print version of the journal are as follows: 1 figure - 650 euro; 2 figures - 900 euro; 3 figures - 1050 euro; 4 figures - 1200 euro; 5 figures - 1350 euro. Cost for each additional color figure will be 150 euro. Unless the color printing charge is paid, color figures will be

automatically adjusted to gray-scale in print. You may opt to send in both black/white figures for print, and color figures for the online PDF (please adjust the figure legend appropriately).